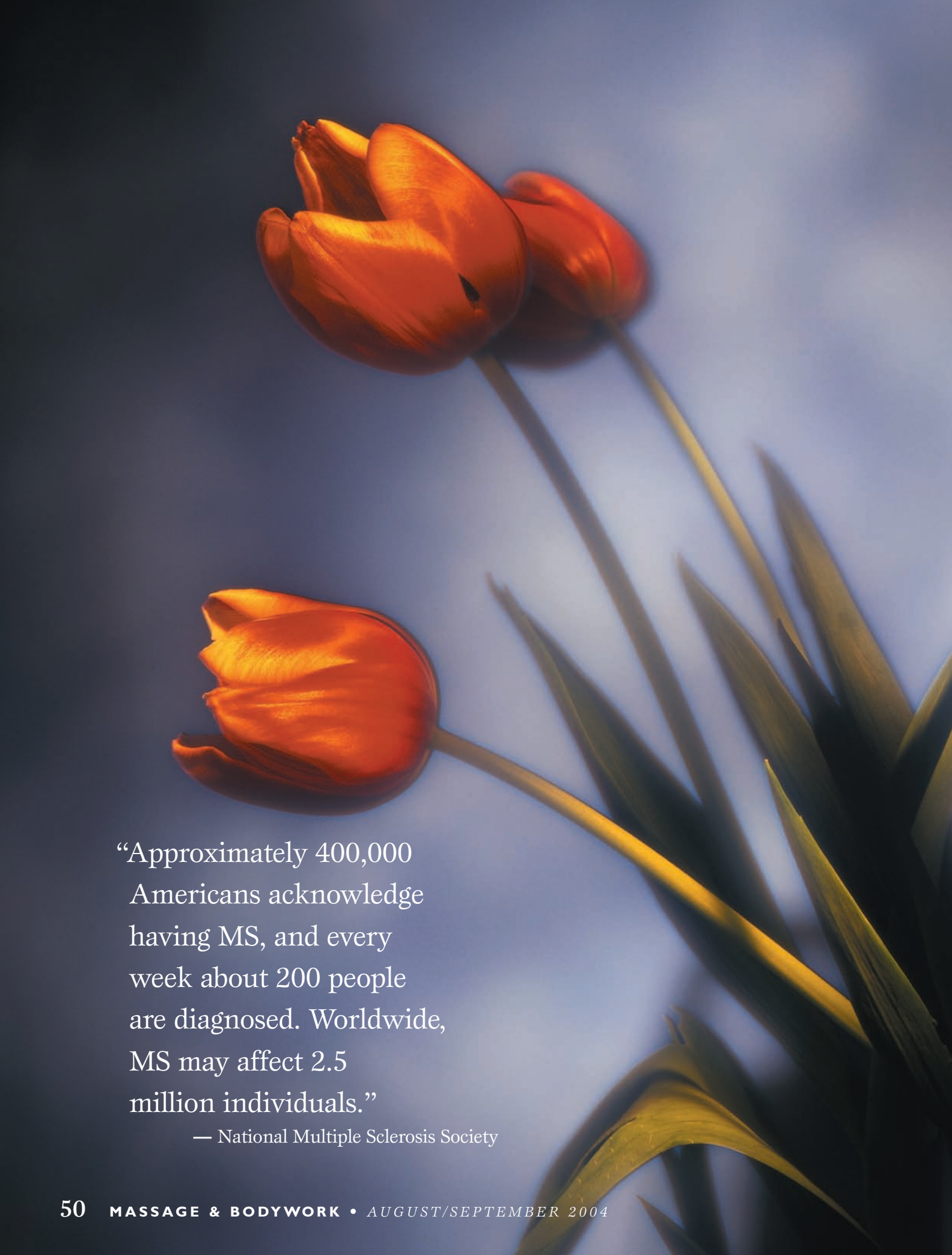
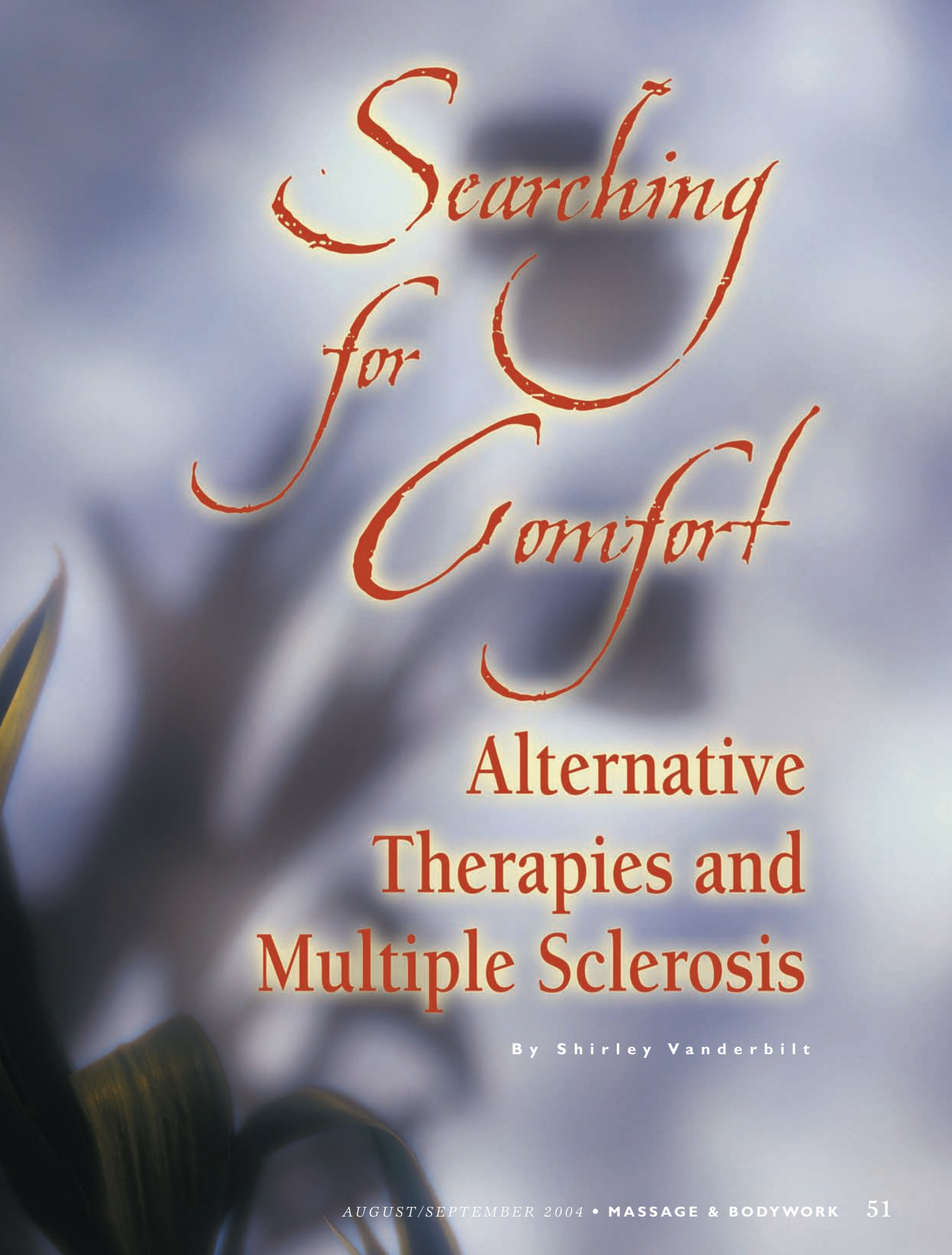


"Approximately 400,000 Americans acknowledge having MS, and every week about 200 people are diagnosed. Worldwide, MS may affect 2.5 million individuals."

— National Multiple Sclerosis Society



Searching for Comfort

Alternative Therapies and Multiple Sclerosis

By Shirley Vanderbilt

One of the most devastating and frustrating diseases of our time, multiple sclerosis (MS) generally targets those in the prime of youth, between ages 20 and 40, wreaking havoc on their bodies and their lives. As yet, there is no cure. Nor is the cause clearly understood, although researchers suspect multiple contributing factors. MS is a chronic neurological disorder in which the immune system apparently and inexplicably attacks the protective myelin sheaths surrounding nerve fibers in the brain and spinal cord. Sclerosis refers to the plagues, or scars, that can form at the site of destruction.

No two cases are alike and, in individual cases, symptoms can vary day to day. The reason lies within the process of the disease itself — the unpredictable, random attack of immune cells on the myelin substance, which can also damage the nerve axon as well. Kalyani Premkumar, M.D., Ph.D., author of *Pathology A to Z — A Handbook for Massage Therapists*, says, "Conduction across the affected neuron is typically slowed. Sometimes spontaneous firing may be seen. Conduction may be altered by changes in body temperature and metabolic environment, explaining the characteristic changes in function from hour to hour. Inflammatory lesions and scars due to MS are scattered throughout the brain. The symptoms vary according to the area and extent of the brain and spinal cord affected."

Multiple Sclerosis Types:

- **Relapsing-Remitting** — Most common form with acute episodes followed by partial or complete recovery.
- **Primary-Progressive** — Slow, continuous progression with no relapse/remission.
- **Secondary-Progressive** — After an initial period of relapsing/remitting, disease takes a progressive course without remission.
- **Progressive-Relapsing** — Continuous worsening from onset, but unlike primary-progressive includes distinct acute flareups and remissions. Although remission may involve some recovery, disease remains progressive.

This wide range of experience accounts for the variance of symptoms and classifications within the diagnosis. (See MS Types above) It also accounts for the fact that some people will have only one episode in their lifetime, while others will have a lifetime of episodes. MS is not fatal, although susceptibility to secondary conditions can sometimes lead to death. For most, lifespan is slightly less than average. More importantly, for those with moderate to severe MS, quality of life is compromised and debilitation affects every aspect from physical functioning and relationships to financial security.

The highest concentration of MS occurs in areas farthest from the equator, in people who have spent their first 15 years of life there. This statistic may be related to two current theories on contributing factors: A virus that thrives in colder regions; and genetic predisposition among some ethnic groups from these areas. Stress has been cited, and is accepted by many, as having potential to bring about MS exacerbations. A recent literature review (March 2004) by Mohr et al. reveals that while non-traumatic stressful events are associated with this increased risk, the relationship "is complex and cannot currently be determined for any individual patient."[1]

With an array of symptoms flaring and abating (see Range of Symptoms, page 58), and at times mimicking other diseases, diagnosing MS can be difficult and frustrating for both patient and physician. Currently, there is no specific test but rather a set of clinical criteria, that include evaluation of symptomatology and diagnostics. Among tests used, Premkumar says, are "Magnetic Resonance Imaging (MRI), evoked responses (investigations that test rate of conduction along specific nerve pathways), and analysis of cerebrospinal fluid."

Neurologist Allen C. Bowling, M.D., Ph.D., adds that diagnosis is typically based on the patient having experienced two separate neurological events with lasting effects (such as on strength, coordination, or vision). But even with one event, he says, if new lesions appear on the MRI, those cases are considered at risk and are now being treated aggressively with MS drugs.

Conventional medical treatment for MS includes drugs aimed at lessening frequency and severity of attacks, thus slowing progression and decreasing potential of permanent damage to the central nervous system. Additionally, drugs may be prescribed for chronic symptoms such as depression and pain.

Alternatives for MS Care

While scientists search for effective treatments and a possible cure, those with MS are desperate to find relief in the present moment with whatever is at hand. Increasingly, they are turning to complementary and alternative medicine (CAM) for help. Bowling's experience with this trend led him to write a book, *Alternative Medicine and Multiple Sclerosis*.

Bowling is medical director of the Rocky Mountain MS Center (RMMSC) in Englewood, Colo. "In talking with patients," he says, "they would often ask about alternative medicine and how it is applied. I realized, when I tried to help answer a question, how complex it was," even with his medical and science background.

The center conducted a survey in 1997 and found that approximately two-thirds of respondents were using alternative therapies. A Canadian survey (2003) found similar results with 70 percent of respondents reporting use of CAM for improved health and symptom management, and most indicating positive effects.[2] Furthering their investigation, Bowling and his associates investigated 50 alternative medicine books for references to MS and found the information confusing, and in some cases potentially dangerous. "It was like the elephant in the living room," he says. "It was not

being addressed correctly." Bowling was inspired to create a reliable resource for the MS population.

In Bowling's book, a wide variety of alternative therapies are covered, with relevant research, indications, and contraindications, as well as some thoughtful guidance for MS patients making the alternative choice. Adding to this, Bowling and Tom Stewart, a physician's assistant and lawyer, created a CAM/MS website documenting objective, unbiased alternative medicine information. The site has grown and serves as a hub for information exchange among more than 17,000 registered users. Anecdotally, Bowling says, patients report that massage decreases muscle spasticity, but he's surprised no studies have been done in this area. According to the RMMSC survey, massage ranks very high on the list of CAM therapies used by MS clients.

RMMSC's resource center is just one of several new CAM-related MS programs emerging across the country. At George Washington University's medical center, the Integrative Medicine Center (IMC) developed a Quality of Life program focused on providing a variety of CAM treatments for MS patients. Program director Susan Silver says the project began as a preliminary study funded by the National Multiple Sclerosis Society (NMSS), with the hypothesis that "individually tailored CAM practices could improve quality of life of client and their caregiver." At project's end, a survey of the experimental group indicated improvement and "everyone said anecdotally they benefitted, and in some cases they continued to use modalities afterward."

Caretakers were also involved, being trained to administer treatments such as reiki and massage. When physically feasible, patients were given an opportunity to reciprocate treatment to caretakers, a powerful esteem-booster in reversing their dependency status. Other modalities offered included acupuncture, meditation, nutrition and supplement counseling, and movement education. "Results are more impressionistic and anecdotal," Silver says, "but certainly positive."

The Therapist's Touch

For the MS patient, a well-being approach for addressing body, mind, and spirit is essential to combating the effects of the disease. Helpful self-care can include a daily routine of tai chi or yoga, meditation, and attention to diet. Some dietary supplements have been found beneficial, and these are reviewed by Bowling and Stewart in their book, *Dietary Supplements and Multiple Sclerosis: A Health Professional's Guide*. While some CAM approaches address specific symptoms, others are aimed at a holistic balancing of the body/mind.

Massage and bodywork are among alternatives recommended by NMSS, but research in these areas is minimal. In a small 1998 study of MS patients, Hernandez-Reif et al. found massage lowered anxiety, improved depressed mood, and increased self-esteem and body image.[3] Another study by Siev-Ner I et al. (2003) of 53 MS

patients showed the effectiveness of reflexology for improving spasticity, paresthesias (numbing and tingling sensations), and urinary symptoms.[4] A 1999 Feldenkrais study of 20 MS patients found benefits of decreased perceived stress and lowered anxiety, but no improvement in physical functioning.[5] Premkumar also notes an aromatherapy massage pilot study in which improvements were indicated for sleep, mobility, and sense of well-being.

Anecdotal reports of success among therapists and clients indicate at least some MS patients are finding a degree of symptomatic relief with CAM. Approaches are varied, but there are common threads, most predominantly in the nurturing care they provide.

Allen Alper, athletic trainer and massage therapist at IMC's MS program, uses a combination of Swedish and other Western methods, including myofascial work and orthopedic massage. Reflecting on the IMC project, he says, "One of the things we found, of all the modalities, was that massage was most immediately effective in relieving symptoms and improving quality of life." The majority of participants were in earlier stages of MS and seemed to benefit more, he says, but even those with mobility problems enjoyed the palliative relief offered by massage.

As a board member for RMMSC, lawyer Dale Trower says his volunteer work with the center's day care program inspired him to pursue massage therapy training. His part-time practice, balanced with legal work, includes a majority of MS clients, most of whom he says are still →

ambulatory. To address spasticity, he uses flexing and range-of-motion work. "On a physical basis, I think it's one of the more beneficial things massage does for MS. Fatigue is often stress-related, so Swedish massage is very effective in helping people relax and de-stress."

In the Northwest, where the incidence of MS is high, massage therapist Fred Baker works with about 17 MS clients each week. Based in Shoreline, Wash., Baker has also trained a dozen other massage therapists who now work with MS clients. He defines his approach as eclectic: muscle energy techniques; passive-positional muscle release; Hanna somatics; and a sparing use of fascial release because, as he says, it hurts. Baker has found one specific approach to be especially helpful for his clients, a C1, C2 technique from Paul St. John's method of neuromuscular therapy. The technique opens up the foramen, an area between the skull and C1 where arteries flow to the brain. "There's more blood flowing to the brain and more energy flowing down the spine to the spinal column," Baker says. "It gives them more energy and allows them to move easier."

Randall Clark, who works hand in hand with St. John teaching and using the method, confirms Baker's claims that patients improve with the C1, C2 technique. "In our mind, there probably is a correlation, but there's no research. Anecdotally, in patients we see that have MS, the symptoms do improve but we can't say as to why." Clark says in every MS client seen at the institute's clinic, there has been distortion at the C1, C2 area. "By aligning that, you increase the blood flow. But what we do is a (whole body) structural balancing, not just balancing at C1, C2."

Multiple Sclerosis Risk Factors

- Affects 2–3 times more women than men.
- Predominant in people of European descent (sometimes found in other ethnic groups).
- More prevalent in extreme northern and southern latitudes.
- Although not yet proven, genetic predisposition may be a factor.

Overall balancing is also an important facet of the Trager approach to relieving MS symptoms. So says Gwen Crowell, a Trager international instructor who also maintains a private practice in Seattle. "There are several things about Trager," she says. It's not just table work, but includes movement and awareness exercises. Through this process, clients learn "to pay attention and to feel more in their body. One aspect that has been very useful is the sense of peacefulness they gain through the work. That they can do something is really important in any kind of chronic illness like that," where there is often no control.

With her extensive MS experience, Crowell says she has learned the importance of balance between releasing spasticity and maintaining enough tone for the client to function. "If you relax someone with MS too much, they can't walk when they get off the table. They use the spasticity to keep them erect." By implementing a reflex response technique, she reduces spasms without decreasing tone. The client is better able to maintain standing balance, and for those who are not ambulatory, core stability is increased so they can sit better. "One of the things people tend to lose is control. You are working with refining the amount of contraction they use with a given movement.

"When your body doesn't respond and you can't feel things as clearly, having a practitioner put their hands on you — where your body is in space — that input seems to be very important. And it's much better than not being touched at all." Crowell emphasizes the need for nonjudgmental support when a client is expressing despair. She also says it's important not to promise more than you can deliver.

Another Seattle-based Trager practitioner and massage therapist, Wimsey Cherrington, generally has between 25-35 MS clients in her caseload. Some are seen pro bono on referral from the local MS association. "A lot of MS patients think all their symptoms are from MS," she says, "and it's true to varying degrees. I look for key biomechanical problems, either totally unrelated to MS or an adaptation from some of their MS problems. Clean those and often it radically improves quality of life." →

Cherrington says she also uses lymph drainage for MS with a great deal of success, especially for patients who say they're having "brain fog," and sometimes includes a bit of cranial work.

The MS Program at Muscle Therapy Northwest in Edmonds, Wash., combines massage and physical therapy modalities with aquatics, acupuncture, and patient education for holistic rehabilitation. "There's no cookbook approach," says clinic administrator Pam Estrella, who has relapsing-remitting MS herself. Speaking to the difficulty many MS patients have regarding job loss, financial stress, and limited medical coverage, she notes the clinic offers pro bono services to clients who otherwise can't afford them. "But they have to participate, too," she adds, emphasizing the need for self-care and responsibility.

Range of Symptoms

In MS, the assault on the myelin sheaths and subsequent interruption of central nervous system communication results in a variety of symptoms, affecting various parts of the body. These can include, but are not limited to:

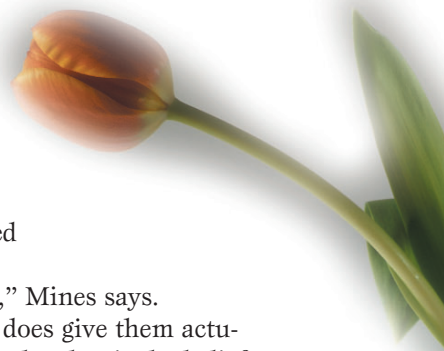
- Numbness and tingling sensations.
- Blurred or double vision, eye pain (optic neuritis).
- Muscle weakness, gait problems.
- Muscle spasticity.
- Sensation of electric shock on neck flexion.
- Tremors.
- Paralysis.
- Fatigue.
- Facial pain and weakness.
- Bowel and bladder dysfunction.
- Depression, mood swings, cognitive impairment.
- Heat sensitivity which can exacerbate symptoms.
- Sexual dysfunction.
- Speech impairment.

On-staff massage practitioner Stephanie Angevine applies training she received from Baker in her work with MS clients. "Positional release helps with ambulation and does have a more prolonged effect," she says. "It's also good for people with MS to have physical therapy as well, depending on the extent MS has impacted them, more to help with core stabilization." Angevine also uses Hanna Somatic Education to help with loss of sensation, and includes effleurage "and more 'feel good' stuff to help with relaxing, to make them feel like they're getting some nurturing touch."

Angevine tailors treatments to the individual and emphasizes respecting comfort boundaries. "When you're confined to a wheelchair or walker, people tend to treat you differently." She sees the therapy session as a safe place where clients can talk, and be heard and respected. Angevine schedules extra time for MS clients, especially those with mobility issues, to allow for a complete session. "It's not fair to compromise their treatment because they have limitations."

The gentleness of energy work is especially appropriate for MS clients. Stephanie Mines, Ph.D., who founded and directs the TARA Approach for resolution of shock and trauma, has designed a protocol focused around common symptomatic needs of people with MS. An expert in treating trauma and abuse with energy, Mines says, "I'm teaching and providing a multifaceted, comprehensive, holistic system. The power is in the self-care aspect. They can actually do something on their own."

Mines, author of *We Are All in Shock: How Overwhelming Experience Shatters You and What You Can Do About It*, says the person with MS is also experiencing shock. Her treatment is based on subtle energy of the eight extraordinary meridians, which she defines as: "Networking meridians, reservoirs of energy designed for overwhelming experience, to deal with something beyond the ordinary. By contacting them you're contacting the system specifically designed for these extraordinary experiences." Clients are taught to identify these areas and simply make contact to create symptomatic shifts for themselves in the moment, she says. For example, if the leg is trembling, the work can be applied for immediate relief. Similarly, she teaches treatment for other symptoms, such as anxiety. "There may be some additional language-oriented tools, but it's the two together.



"The technique is secondary," Mines says. "It's very important because it does give them actual change. But what really pervades that is the belief that they can heal themselves through their own intention. To heal means surrendering in some regard — to accept it, not be undermined by it, see it as a gateway. That opens the neurotransmitters when you have that positive embracing. Your neurology changes, you come out of the shock response ruled by the primitive brain. The goal is not only symptomatic relief but the true goal is a higher neurological functioning that allows you to be creative with your life, and that is what coming out of shock is all about."

Although in many massage schools training for MS work is minimal or absent, some specialized programs are available. At Sutherland-Chan School in Toronto, Canada, executive director Debra Curties, R.M.T., offers a comprehensive course that includes clinical theory and pathophysiology of the disease, followed by clinical assessment and hands-on work at the school's MS Society clinic. Issues such as range of symptoms and the exacerbation/remission cycle are covered along with clinical scenarios highlighting therapeutic application and benefits. An eight-week rotation through the MS clinic gives students an opportunity to experience the ever-changing face of MS.

"Students learn about working with spasticity and rigidity and sensory abnormalities," Curties says. "They put together the various tools they've learned in their two years of training. It all comes together in a situation as complex as the MS clinic. Each client seems to pose a different set of challenges."

Cautions and Contraindications

Although there is no all-encompassing protocol for treating MS, there are specific factors to be considered in addition to the usual precautions applicable to bodywork. Premkumar, whose pathology book is currently being revised and updated for a third edition, says one of the most important guidelines for a therapist working with the MS client is to be mindful of the changing quality of symptom presentation. Each visit requires a thorough assessment, she says, "as the symptoms vary and progress unpredictability."

Heat sensitivity is a primary issue. "Since hot or cold temperatures can make the symptoms worse, avoid using high heat or cold therapy," Premkumar says. This precaution also applies to the environment of the treatment room.

Curties says MS clients "tend to fatigue easily and profoundly. It's a fatigue most of the rest of us never experience." She recommends designing a session's length and rigor around the client's energy levels. "One thing we tell students is massage is a very complex activity for the brain and in a person with MS, the brain has trouble organizing its responses." Premkumar also recommends shorter sessions, half-hour in length and twice weekly, "but the treatment needs to be ongoing." She also advises against deep tissue techniques, with special concern for areas where sensation is diminished.

"Since any kind of infection can precipitate an attack, and since these clients may be on corticosteroids which depresses immunity," Premkumar says, "avoid treating clients with MS when you have any kind of infection." She also suggests therapists be on the lookout for decubitus ulcers that can develop in less mobile MS patients and, "avoid massage over a wide area if such ulcers are present."

While emotional issues are certainly prevalent for MS clients, they can also arise in the therapist. "I've had patients who have died," Cherrington says. "It's really important to have emotional support as a practitioner. It's also really important to be clear about boundary setting, using active listening, and knowing when to refer."

Flareup episodes require particular attention. Pathology expert Ruth Werner, in an article in *Massage Today* (2002), recommends holding off on massage during an exacerbation. "Some varieties of energetic work may be appropriate during MS flares, as long as the process is respected and the client is not overwhelmed or overchallenged by the stimulus being supplied."[6] In another *Massage Today* article (2001), Ben Benjamin concurs, also noting that even during subacute stages, overstimulation of the client is a concern and "can result in painful and uncontrolled muscle spasms."[7]

Trower says if the client has recently experienced an exacerbation, he seeks advice from the physician regarding continuation of massage. "One just doesn't know at that time. It's like after an injury. With most injuries in the acute phase, massage is not indicated."

For Curties, the flareup stage is not an absolute contraindication. "But you have to stop and think about it. Would you tax their body too much? They're taking very heavy duty anti-inflammatory medications. You're looking more at the benefits of gentle soothing touch in terms of reducing pain, sleeping better, feeling more nurtured rather than any specific treatment goals. For some clients it's too much. It's really a case-by-case situation. It's important to lighten up and step back from any penetrating kind of work. It's more supporting the person at that stage."

Curties adds, "I think the main thing is to understand that there are a lot of different pieces of knowledge that come together when working with MS." She advises therapists to pursue additional training, for example in working with spasticity, and to be mindful that there is no "MS treatment." M&B

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