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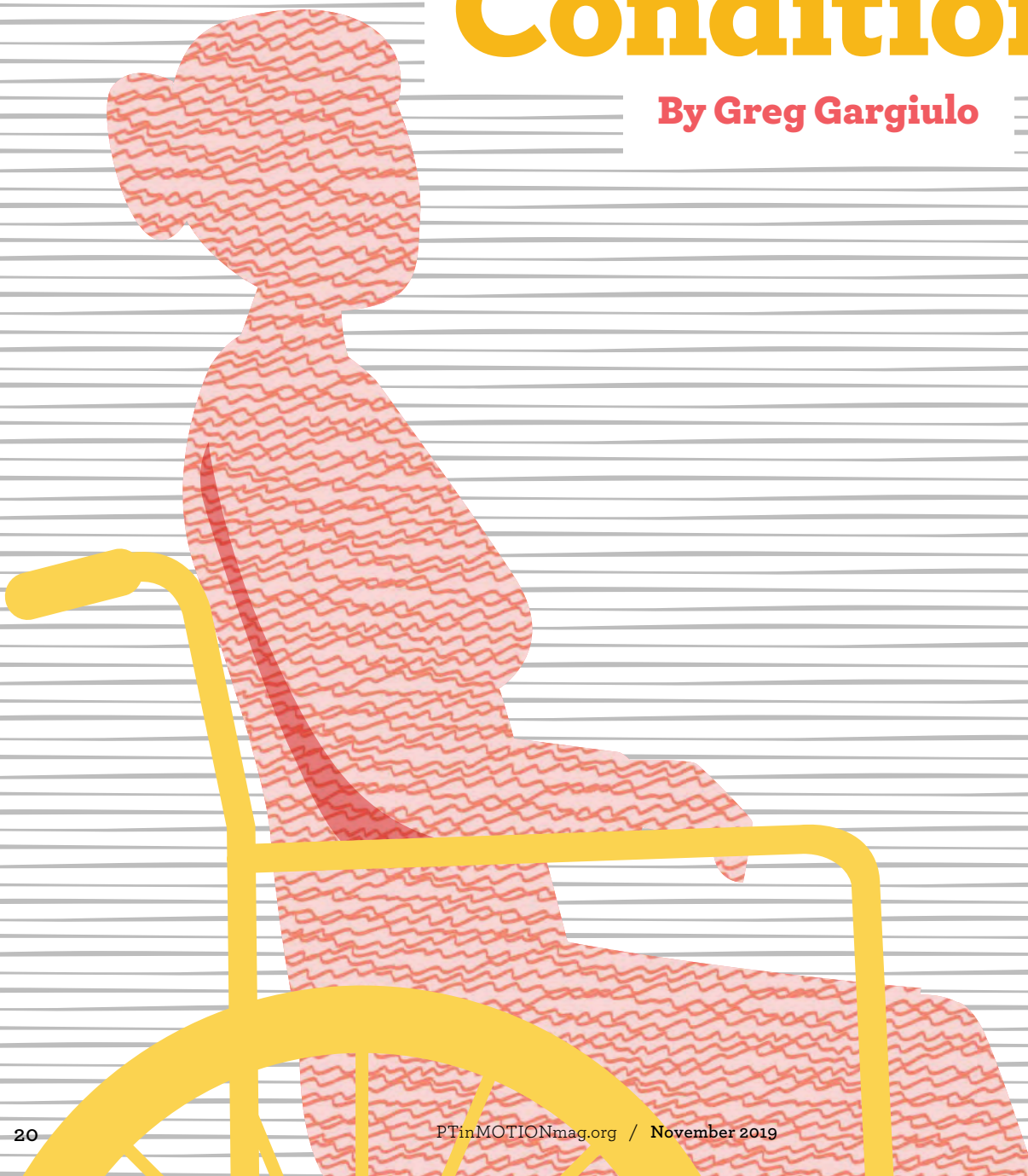
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TREATING PATIENTS WITH **Autoimmune** **Conditions**

By Greg Gargiulo





Multiple sclerosis. Guillain-Barré syndrome. Lupus. Rheumatoid arthritis. Addison disease. There are more than 100 autoimmune diseases that cause the body's immune system to attack and destroy healthy body tissue by mistake. What should PTs know about managing treatment for people who have them?

In 1991, Kimberly Steinbarger, PT, MHS, had a minor injury that did not heal as expected. She had jammed her finger in a door and, 2 weeks later, found it odd that the swelling had not subsided. Making matters more alarming, one morning she noticed that the same finger on her other hand had swelled up.

"I was 24, so I was too old for juvenile rheumatoid arthritis and too young for adult rheumatoid arthritis, and I had no family history of arthritis," she explains.

Steinbarger, who had been a physical therapist (PT) for just 2 years, was shocked when a rheumatologist eventually diagnosed her with rheumatoid arthritis (RA).

"It was a huge blow, and it took me a long time to get over it," Steinbarger says. "At the time, there weren't many resources available to help me. Maybe there was an Arthritis Foundation pamphlet in the physician's office, but my course of treatment was more based on what drugs to try next. There really was no mention of exercise or physical activity back then. If you wanted to figure out how to manage your life, you had to seek outside resources on your own."

RA is the most common of more than 100 autoimmune diseases.^{1,2} While each is unique, they all essentially result from an immune disorder—faulty recognition by the immune system. Instead of differentiating between foreign and native cells, as the body usually does, the immune system perceives parts of the body such as joints, skin, or

“Physical therapists have a unique opportunity to help patients vastly improve their health status by helping them understand that exercise and activity are medicine.”

— Ben Shatto



other organs to be dangerous outsiders and attacks healthy cells by releasing autoantibodies.³

Autoimmune diseases—which include multiple sclerosis (MS), type 1 diabetes, lupus, Guillain-Barré syndrome (GBS), vasculitis, autoimmune thyroid disease, psoriasis, and celiac disease—affect more than 23.5 million Americans.⁴ Symptoms vary widely, depending on which tissue(s) and organ(s) are affected, but several features are universal. Most patients experience inflammation, fatigue, swelling, and muscle and/or joint pain, all of which follow a pattern of remissions and flareups.^{1,5}

Treatment Advances

Treatment for autoimmune diseases has come a long way since Steinbarger first was diagnosed with RA 28 years ago. While medications remain the mainstay of most treatment plans, physical activity and exercise increasingly have become recognized as safe, effective measures for reducing symptoms and improving quality of life.⁶ Not surprisingly, physical therapy has come to play a more significant role in management of these conditions, in part because of its focus on improving and enhancing movement.

“Physical therapists have a unique opportunity to help patients vastly improve their health status by helping

them understand that exercise and activity are medicine,” says Ben Shatto, PT, DPT, owner of The Medical Fitness Center in Eagle, Idaho. He specializes in orthopedic conditions and frequently works with patients with various autoimmune conditions, including fibromyalgia, RA, Crohn’s disease/ulcerative colitis, and lupus. Shatto is a board-certified clinical specialist in orthopaedic physical therapy and a certified strength and conditioning specialist.

In most cases, seeing a PT may not be a top priority for either the patients themselves or their care team. Consequently, those patients may not be referred to physical therapy immediately—or at all, unless another health issue springs up.

“As physical therapists, we typically are not working with the condition directly. We more often are seeing patients for other issues and they just happen to also have an autoimmune disease,” Shatto says. “But that person’s autoimmune disease typically is a significant comorbidity that will affect his or her care.”

Is Physical Therapy Appropriate?

Determining whether the patient is a good candidate for physical therapy depends largely on the initial evaluation, which may occur with another specialist or in a hospital setting.

For Kristin Parlman, PT, DPT, a board-certified neurologic clinical specialist at Massachusetts General Hospital in Boston, several variables must be considered during the evaluation process. Individuals recently diagnosed with MS, GBS, and myasthenia gravis account for a substantial portion of her patient population with neurologic autoimmune conditions. Each requires special attention.

“Our role at the inpatient stage is to develop a treatment plan to maximize function that’s individual for that patient for their life role. We do this by impairment-level and functional testing and monitoring their response through such measures as hemodynamics, rating of perceived exertion, and fatigue,” she says. “We’re seeing them within the first couple days of their diagnosis, when their clinical status is still pretty dynamic. For someone with Guillain-Barré, for example, their condition may still be progressing and their strength and sensation may be declining. We need to continuously monitor this in order to develop a safe and effective treatment plan. Education is a big component of our intervention in each of these diagnoses. It’s very individual in terms of the readiness of the patient as to how much we educate now, versus referring them to a PT in the future to address exercise when they’re ready.”

Once a health care provider determines that a patient is ready for

physical therapy and makes the appropriate referral, individualizing patient care remains crucial in treatment decisions.

“Performing a complete and thorough evaluation is extremely important to provide an individualized treatment program for each patient,” says Maria Rundell, PT, DPT. Rundell, the outpatient physical therapy lead at Encompass Health Rehabilitation Hospital in Colorado Springs, Colorado, has extensive experience treating patients with MS and other autoimmune diseases, including chronic inflammatory demyelinating polyneuropathy, Graves’ disease, and RA. She is a board-certified clinical specialist in neurologic physical therapy and also is a multiple sclerosis certified specialist.

“During the subjective portion of the evaluation, fatigue, heat sensitivity, pain, and bowel and bladder issues are

addressed, and we also identify patient needs for services from other health care providers.” Rundell says.

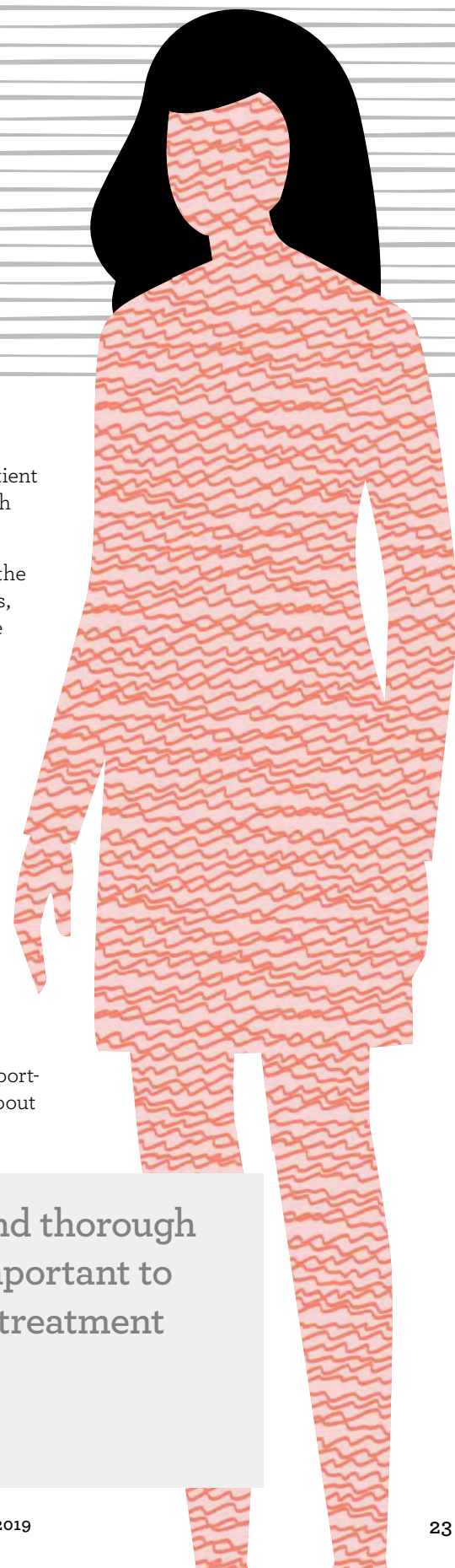
After obtaining a clear picture of the patient’s impairments, capabilities, and goals, patient education is the next step. While this applies to all physical therapy patients, the PTs interviewed for this article agree that it is especially vital for those with autoimmune conditions because of how severely affected some will be.

“For the setting I was in, the most important intervention was education—education about the disease, the disease process, patient self-advocacy, and how patients can learn more about their condition from appropriate sources,” says Kerri Sowers PT, DPT, PhD. “It’s also important,” she adds, “to teach patients about



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– **Maura Iversen**

the value of mobility, movement, and exercise, and how to appropriately start those activities.” Sowers is a board-certified clinical specialist in neurologic physical therapy.

Sowers was working at a level II trauma hospital and comprehensive stroke center, where she often saw patients with MS, RA, dermatomyositis, lupus, transverse myelitis, and other autoimmune diseases. (While she still does per diem and pro bono work, she now is an associate professor in the School of Health Sciences at Stockton University in Galloway, New Jersey.)

Sowers also has relevant research experience, having completed her dissertation at Nova Southeastern University on “The Impact of an Exercise Program on Stress, Fatigue, and Quality of Life for Individuals Living With Primary Immunodeficiency Disease.”⁷

Part of what drove her to investigate exercise for patients with compromised immune systems was her personal connection to the topic as a clinician and a patient. For the past 7 years, Sowers has dealt with a primary immunodeficiency (PID) called common variable immunodeficiency (CVID).

PIDs comprise more than 350 rare, chronic disorders—CVID is the most common⁸—that are characterized by part of the body’s immune system being absent or malfunctioning.⁹

PIDs are not autoimmune disorders themselves, but since they feature a dysfunctional immune system, many PIDs patients also will have autoimmune conditions and complications, Sowers explains.

Since learning of her CVID diagnosis—which took 2 years and a battery of tests to reach—Sowers has discovered that she needs to keep moving regularly in order to cope with the complicated course of her condition.

“For me, exercise is absolutely necessary, both physically and mentally, so I do lots of farm chores multiple times a day, and I ride horses 5 or 6 days a week,” she says. “I may feel more physically tired when I exercise, but it’s a ‘good’ tired. If I don’t exercise, I actually feel stiffer and more emotionally tired.”

Sowers’ own positive response to exercise, as well as her dissatisfaction with the available data on CVID, spurred her dissertation. Since completing the study, she’s come closer to establishing an effective formula for patients with PIDs and autoimmune disorders.

“My exercise prescription—which is influenced by my research findings—is to start with a lower-intensity, low-duration, high-frequency exercise program,” she says. “It’s also critical to find exercises that patients are interested in, so that they can engage without seeing it as exercise. Physical therapists also

can work with patients to build up mobility throughout their usual day—by, say, taking the stairs instead of the elevator, or parking farther away from their building.”

Maura Iversen, PT, DPT, SD, MPH, FAPTA, also has dedicated much of her professional career to studying and promoting exercise in this population. She’s been working in rheumatology for more than 25 years and obtained a doctor of science degree from Harvard University so that she could design clinical trials to test nonpharmacological interventions for patients with RA and other related conditions. She is the associate dean of clinical education, rehabilitation, and new initiatives at Bouvé College of Health Sciences at Northeastern University, and a behavioral scientist in rheumatology

at Brigham & Women’s Hospital. (Both are in Boston.)

“Keeping moving is an important component of arthritis self-management,” she says. “Given the autoimmune response associated with RA, joint involvement, and cardiovascular and pulmonary complications of the disease, patients will benefit from a combination of joint range-of-motion exercises, aerobic conditioning, and strengthening exercises.”

Overcoming Barriers to Interventions


Evidence to support exercise and physical activity for RA and other immune-mediated conditions is substantial, with multiple studies showing that specific exercises and general

activity recommendations can lead to a variety of physical and psychological benefits.^{6,10-15} But because of the complex and multifaceted nature of these conditions, PTs must take into account numerous considerations when prescribing exercise.

Among these, fatigue is a leading obstacle.

“I don’t think I’ve met a patient—clinically or in my research—with an autoimmune or immune issue who didn’t have some degree of fatigue,” Sowers says. “When your body is in a constant ‘fight’ state or is constantly attacking itself, systemic inflammation can be a big contributor to fatigue in these patients.”

Research helps quantify the scope of this issue. According to an online




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Symmetry Table	OneT01.Fsx Tester One	OneT02.Fsx Tester One	Difference #2-#1
Step Time (%)	96.7	97.1	0.4
Step Length (%)	97.3	98.2	0.8
Step Velocity (%)	99.4	95.3	-4.1
Step Width (%)	93.3	96.0	2.7
Stride Time (%)	100.0	98.9	-1.1
Stride Length (%)	97.7	98.6	0.9
Stride Velocity (%)	97.7	99.7	1.9
Maximum Force (%)	95.5	93.9	-1.5
Stance Time (%)	97.5	97.9	0.4
Swing Time (%)	96.1	93.6	-2.4



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survey of 7,838 patients with autoimmune diseases conducted by the American Autoimmune Disease Related Diseases Association (AARDA), 98% reported experiencing fatigue—with 89% calling it a “major issue” and 59% saying it is “probably the most debilitating symptom of having an autoimmune disorder.”¹⁶

Steinbarger can attest to this burden.

“Fatigue has been my biggest issue, and it’s a factor that PTs and physicians often don’t address,” she says. “I have joint pain most days, and I can deal with that. But it’s not the same with fatigue. If you’re tired and you can barely get your head off the pillow, that’s a totally different thing to manage.”

Steinbarger is the director of clinical education of the School of Physical Therapy at Husson University in Bangor, Maine. She made the transition into education after realizing she wasn’t going to be able to perform all the manual techniques and heavy lifting she needed to as a PT, although she still runs the pro bono clinic at Husson. In her academic position, she guides students and newer PTs through how to handle fatigue and other challenges that are likely to arise in patients with compromised immune systems.

“I often tell my students, ‘If you want to give patients with autoimmune conditions an exercise but they have problems with fatigue, it had better be a damn good exercise, because you

can’t give them 15 exercises,” she says. “You need to pick the 2 best tricks in your bag, because if they’re going to expend energy on it, it needs to be worth their time.”

But fatigue certainly isn’t the only commonly encountered hurdle to providing care to this patient population.

“We also need to teach patients about their condition and what to do if they have flare-ups, because even if their medication is working well, they’re still going to have flares,” Steinbarger says.

For Iversen, it’s about knowing how to respond appropriately. “In the case of a flare, joints are painful and swollen, and patients often experience malaise. So the exercise prescription needs to be adapted to reduce repetitions, frequency, intensity, and duration. Once the disease is under control, patient can be directed to increase exercise parameters based on their current physical condition,” she says.

Between fatigue, flare-ups, and other potential problems that immune-mediated disorders can bring about, most patients’ symptoms extend beyond the physical realm. PTs should be prepared to handle these issues, too.

“There is a huge emotional component when treating patients with autoimmune and immune disorders,” Sowers says. “Many patients have ‘invisible illnesses,’ which are known to have a stigma associated with them. They also live with the anticipation that they may

go into a flare or develop a complication or associated condition at any time, which can contribute to higher levels of stress and, in effect, make autoimmune issues worse.”

Both Iversen and Steinbarger recommend screening for depression because of how frequently it occurs in these patients. If a patient is depressed, they advise, the PT needs to help that individual recognize that exercise can help lessen depression as well as produce physical changes needed to manage the disease. It also is paramount that PTs make referrals, when appropriate, to a mental health professional or, if a patient is more comfortable there, a support group.

“Part of my job as physical therapist is knowing what’s available in my community and what’s most appropriate for each patient, and telling them where to get questions answered and how to find other people like them,” Steinbarger says.

Since PTs often are just one element of the health management needed, some go beyond the referral alone and work with other health care professionals as part of a more holistic and comprehensive model that covers multiple aspects of their patients’ care.

Rundell, for example, is a member of a team at her hospital. “It has been found that a multi-dimensional team approach is the most effective and efficient way of treating people with MS, and it empowers the patient to become



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– Kimberly Steinbarger

an integral part of the team,” she says. “We have physical, occupational, and speech therapy services in our clinic, and we’ve also developed relationships with other health care providers in our community who are familiar with the MS population.”

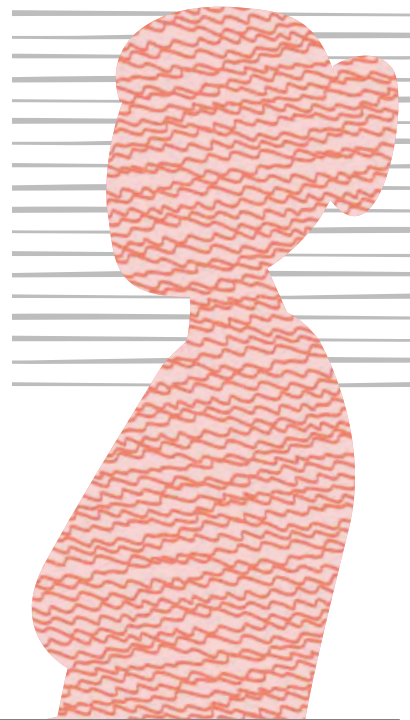
This team also could include rheumatologists, neurologists, mental health professionals, dietitians, nutritionists, and others. Diet is vitally important for most patients with autoimmune diseases, and some evidence suggests that certain foods—especially high-sugar, high-salt, and processed items—may contribute to the development of autoimmune conditions.¹⁷ But, says Sowers, “I leave specific diet advice to those who are trained in that area.”

In an ideal world, the referral process would flow in the opposite direction as

well, with health care providers directing appropriate patients to physical therapy. But whether it’s because of insurance restrictions, providers not realizing the benefits of therapy, or for other reasons, this flow of patients often doesn’t happen.

“I asked my rheumatologist if he refers people to occupational and physical therapy right after giving them an RA diagnosis, and he said, ‘I’d love to, but I can’t, because insurance won’t cover it because nothing appears wrong at that moment,’” Steinbarger explains. “But there is something wrong even if they aren’t having a flare. These patients should be referred to physical and occupational therapists right away.”

Failure to properly refer deserving patients to physical therapy is a barrier to care that, to Steinbarger, shows that



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while the medical field has come a long way, “we’re still not where we should be.”

Even when physical therapy can be incorporated into the treatment plan, another obstacle PTs may face is appropriately managing patients’ expectations. Since cures have yet to be discovered for many autoimmune diseases, most patients must manage their condition and all of its implications for life—which can be daunting. PTs can help by teaching patients “separate out exactly why they are having physical therapy and what it can accomplish,” Shatto says.

Parlman says, “It’s helping people to prognosticate what their potential is. Identifying each patient’s individual outcome is about understanding the trajectory of the illness as it pertains to that person.”

Navigating a “Bumpy Road”

For Rundell and her team, the goal of comprehensive MS care is to improve patients’ functional independence and enhance their participation in life, with an emphasis on education and self-management. They also encourage patients to engage in personal and social activities, and to work toward maintaining a good quality of life and independence.

Shatto has found that the patients who best cope with their condition tend to be very motivated but also realistic about the bumpiness of the road ahead.

“They seem to have a strong psychological resilience, and will get right back at it as soon as their body will allow,” he says. “I’m not sure if this was something they were born with or just developed over time, but they cope well and are not easily discouraged.”

It appears that Sowers and Steinbarger could readily be placed into this category, as they continue to remain active in their educational, research, and clinical duties—as well as their social

life and family commitments—despite their physical limitations.

“I am very active and tend to overdo it, which occasionally my body reminds me of,” Sowers says. “But I try to not let CVID and fears of getting sick interfere with my life—that is a purposeful effort.”

Steinbarger thinks that to be successful, patients need to be able to modify their activities so they can still do what they need to do in work, play, and family life.

“I can’t play softball anymore, but I am able to ride my bike, and I like to cook,” she says. “So, I have electric mixers and all kinds of other specialized tools in my kitchen. I would tell people: If there’s something you like to do, that’s what you want to try to achieve with appropriate modifications, because it could be a big loss if you can’t do those things.”

Through her many roles, Steinbarger seeks to provide the guidance to patients that was missing when she first was diagnosed with RA, so that they can understand the value of a path that includes physical therapy and a more active lifestyle.

“These patients need someone to walk through their lives with them to see where they can make those changes, because the path is different for everybody,” she says. ■

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