A Therapy for your Functions

BY CHRIS LOMBARDI

Carol Wilkerson lay on her back, her legs lifted toward the ceiling. As her physical therapist called out directions, she pressed her legs together tighter and breathed some more. She lifted her arms and waved them in a circle, up and around her ears and back.

"Again."

A former advertising executive, Carol had never thought she'd be in this position.

It had been quite a journey to the physical therapy clinic of Cinda Hugos, MS, PT, at the MS Center of Oregon Health & Science University. Carol, who was diagnosed with MS in 1993, had been prescribed Betaseron, but little else. By the time she and her husband of 34 years moved to the West Coast in 2001, her condition had progressed. Her new neurologist sent her out for a new round of tests, with Cinda and other therapists. "I learned a lot about myself that I didn't know," she said.

She discovered that she had limited movement in her left leg, increasing dif-

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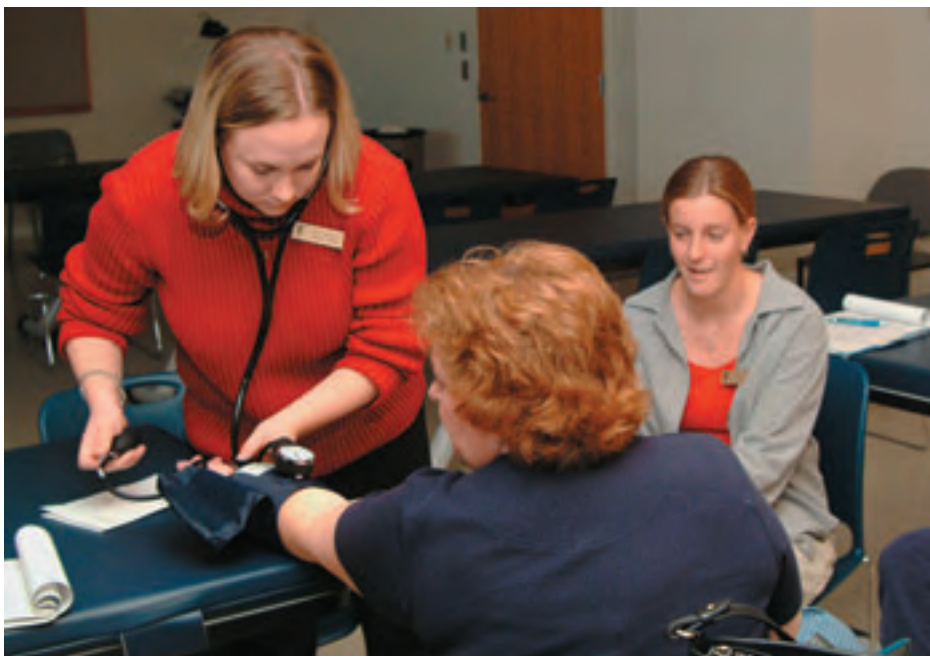
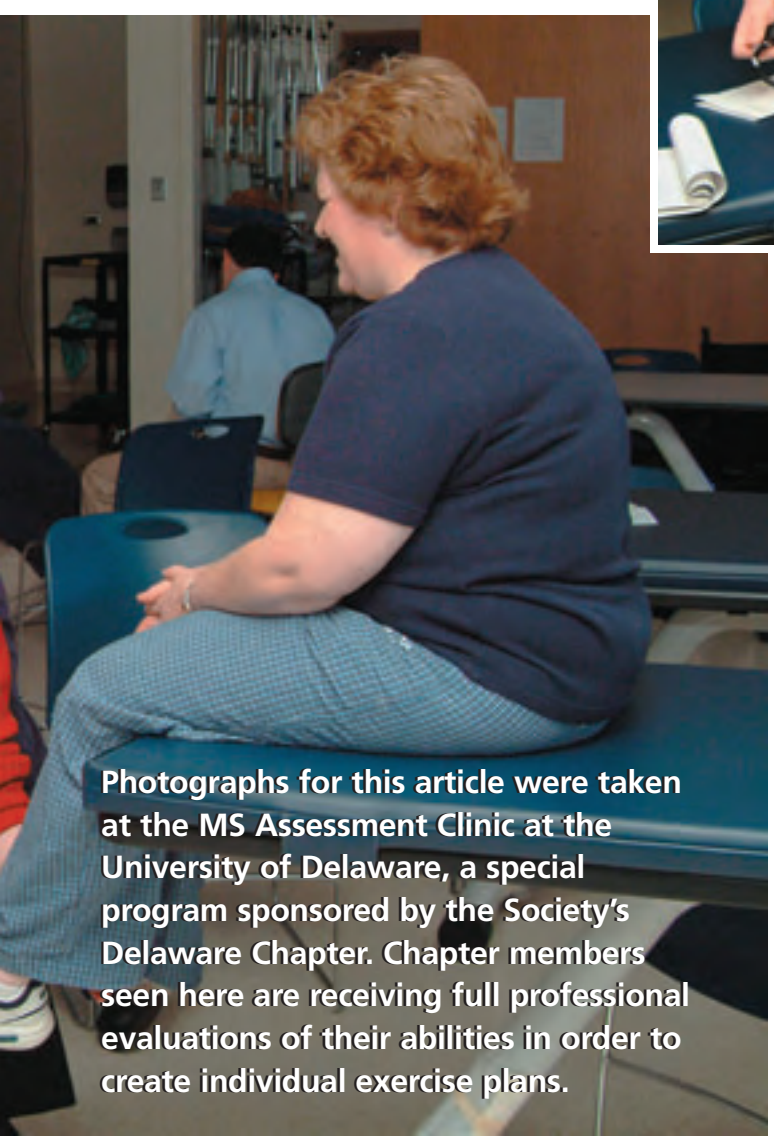
ficulty with her left hand, and balance issues. And she learned that her memory problems and fatigue, which she had regarded as a side effect of her busy lifestyle, were instead likely to be part of her MS—and something she could learn to manage better.

Cinda wasn't her first physical therapist, Carol said, but she was the best that Carol had worked with. The movements described above, which incorporate some of the century-old Pilates training system, were part of an overall routine Cinda recommended for Carol, a set of stretching and strengthening moves designed to help Carol regain some of the strength and flexibility she had lost.





Photographs for this article were taken at the MS Assessment Clinic at the University of Delaware, a special program sponsored by the Society's Delaware Chapter. Chapter members seen here are receiving full professional evaluations of their abilities in order to create individual exercise plans.

Then Cinda introduced Carol to a research project studying the use of yoga, customized for people with MS. After only a few months, Carol said, she felt "much stronger and much more secure." Now she knows which exercises fatigue her and which help strengthen her muscles without tiring her out. And she approaches each day with a lot more confidence. Physical therapy has been key to all that progress, she said.

It all starts with an assessment

People with MS may need physical therapy at any point: upon diagnosis, after an exacerbation, or at any time thereafter. "We usually see people who've suffered some sort of functional loss," said Ken Seaman, MA, PT, coordinator of Clinical Education

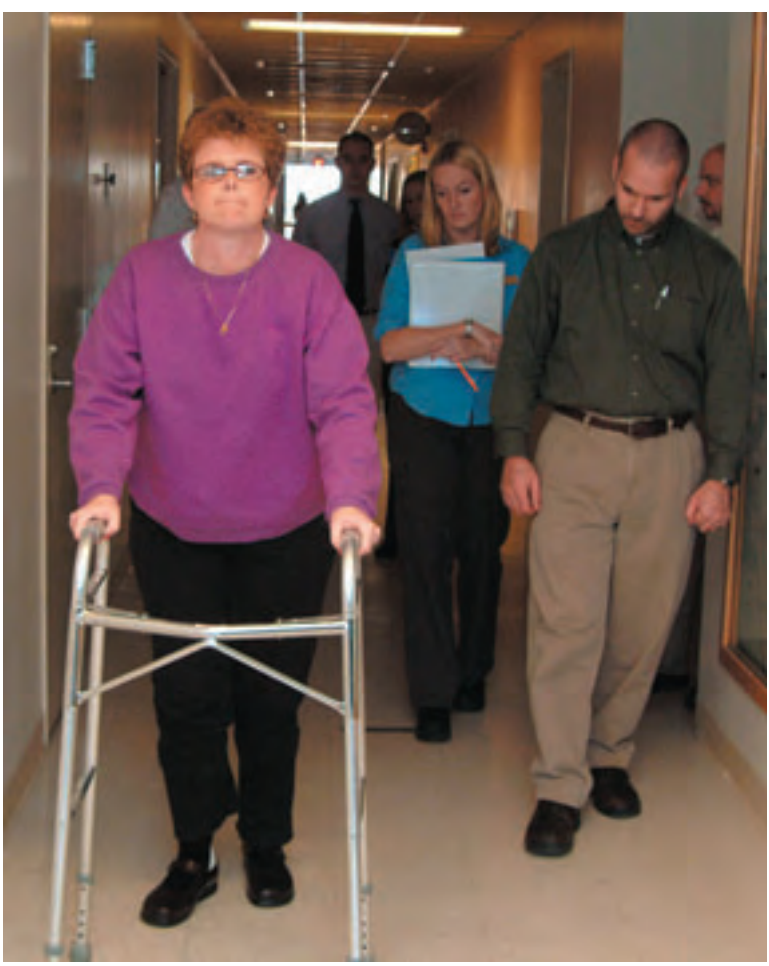
and director of the MS Assessment Clinic at the University of Delaware. "We see people with balance problems, spasticity that affects gait, increased weakness—even a wheelchair that doesn't fit right."

Physical therapy is only one component of rehabilitation, the overall process that Dr. George H. Kraft, of the Western MS Center at the University of Washington, has called "the only means of restoring function in MS patients." Dr. Kraft is a physiatrist—a physician who manages a patient's rehabilitation program, making referrals to physical and occupational therapists, counselors, and medication specialists (pharmacists who evaluate current prescriptions and fine-tune dosages). Dr. Kraft is proud that his program almost always leads to measurable improvements in his patients' lives. Incremental progress, increasing the level of functioning, is a commonsense and completely doable goal. Yes, in MS.

Ken Seaman's clinic sees five patients a month, the vast majority of them in the progressive stage of the disease. "Assessment and referral is all we do—we don't treat here." Participants at his Delaware clinic will see a nutritionist, an occupational therapist, a psychologist, and even an optometrist. Still, he says, his assessment clinic "started out with evaluations for physical therapy," and PT is an integral part of the recommendations his clinic develops for every participant.

Then the referrals are made—often to both a physical therapist and an occupational therapist. "Typically, physical therapists work with lower extremities, with gait and mobility," said Patricia Kennedy, RN, CNP, MSCN, director of Patient Education and nurse practitioner at the Rocky Mountain MS Center in Englewood, Colorado. "Occupational therapists work more on activities of daily life, energy conservation, and eye–hand coordination."

The physical therapy assessment typically involves gait analysis (watching the person walk to see if muscles are being used properly or bones stressed); strength and flexibility tests; and tests to gauge how much energy someone is using to perform certain tasks. "We put an oxygen telemetry unit on them to assess energy consumption and effort," Seaman said. Any assistive equipment being used is also evaluated.



"To get around the mall"

"We also ask what their goals are," Seaman added. "We had one fellow in here whose main goal was to get around the mall with his toddler without becoming exhausted." For others, it might be regaining their balance or improving their driving.

The physical therapist then maps out a plan for real, tangible improvement in quality of life. "Everyone gets a home program," Seaman said, "whatever their level of capacity. If you use a wheelchair all the time, we might suggest you use it in different ways, both at home and out and about."

The plan may include:

- an **exercise bike**, to regulate your heart rate before other exercise;
- **simple mat exercises,** for stretching and gentle strengthening;
- **stepping and marching**, to improve balance, coordination, leg strength, and hip flexibility;
- **physioballs**, to help with strength, balance, and flexibility;
- **free weights, weight machines, and resistive exercise bands**, to gradually condition the muscles;
- **aquatherapy**, or water exercise (ranging from simple underwater stretching to something quite aerobic). Water can enable you to exercise muscles you may have trouble moving on dry land; and
- **yoga, Pilates**, or **tai chi**, which emphasize stretching and strengthening.

"Still feels like work"

Each program is chosen carefully and tailored to the individual's ability. Of course, it usually feels like work. "People need to be convinced that their lives can be better if they work at it," Patricia Kennedy said. "Some say, 'Give me a pill or don't bother.'"

Kennedy is also concerned about people who are resistant to the other great tool for improving physical function: adaptive equipment. "The closets of America are filled with adaptive equipment that is never used."

The therapist will identify what equipment might be most helpful, or if any changes are needed in an existing setup. Sometimes it's overcoming that initial resistance: the man who wanted to get around the mall with his toddler, for example, "showed up with a walking stick," perhaps more elegant but less useful than a cane. For him, the solution turned out to be a wheelchair that he could use to conserve his strength.

An individual's program may include:

- **Small changes.** Braces or orthotic devices can help with foot drop.
- **Canes and walkers.** They can be a temporary solution, part of an overall strategy, or a way not to spend **all** your time sitting in a wheelchair or scooter.
- **Adjustments to wheelchairs.** Size, weight, and ergonomic considerations can all maximize the usefulness of this equipment. For some, an electric wheelchair is the best choice. For others, a manual one, which will make the person work a little harder, is preferable.
- **Adapting your car so you can keep driving.** Options include hand controls, knobs on the steering wheel, or adjustments to compensate for vision problems.

Driving, necessary for so much of American life, is a particular focus for many physical and occupational therapists. The Kessler Medical Rehabilitation Research and Education Corporation, in West Orange, New Jersey, is now in the midst of a second major grant to develop interventions to "keep people on the road," according to principal investigator Maria T. Schultheis, PhD. The Kessler project emphasizes both physical interventions and cognitive issues—since the slower response time that often comes with MS can badly affect driving.

Making sure it's paid for

Physical therapists, physiatrists, devices to help people ambulate, drive, or exercise—how much of this is covered by insurance?

Most plans, including Medicare, are usually willing to pay for physical therapy upon diagnosis or after an exacerbation, although many limit the number of sessions, have a dollar limit per year, or even a maximum lifetime benefit per patient. Sometimes, however, the goals of therapy are maintenance or prevention, and these are not as attractive to insurers.

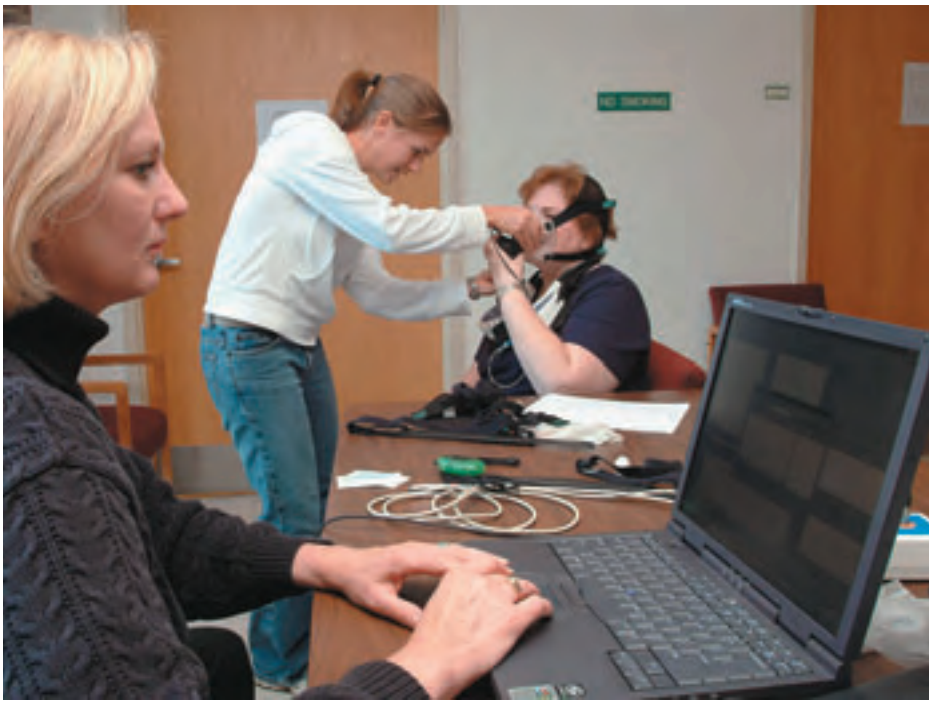
Until last December, Medicare had an annual cap of $1,500 for physical, occupational, or speech/language therapy. "Some folks never started, or stopped and restarted therapy each year," said Dorothy Northrop, MSW, ACSW, director of Clinical Programs for the National MS Society. Now that annual cap has been lifted. But physician prescription is still required.

"A referring physician needs to be a vigorous advocate," Northrop said. "PT not only helps people with MS maintain functional status, it helps prevent expensive secondary medical conditions. Physicians must forcefully communicate this to insurers."

In fact, physicians need to make a strong case for **any** non-emergency service. "If there is no exacerbation, they may write about a medical event," Northrop said. They can also argue that therapy not expected to restore function can maximize physical potential and prevent costly complications. It may also cancel the need for more expensive medications. Doctors also need to argue for coverage of changes in adaptive equipment: "The inclination of the insurance company is to say, 'The patient already has one of those!' and not to see the need for adjustments."

"People need to pay particular attention to what their policy says," Northrop added. "A policy with a cheaper premium is undoubtedly more restrictive. People need to look at their fine print." That includes coverage for assistive devices, often known as "durable medical equipment", or DME. Any policy a person with MS takes out should have coverage for such equipment, just in case.

Most of the practitioners interviewed for this article are frequently frustrated by the insurance barrier. "Ideally, patients should be entitled to physical therapy intermittently throughout the course of their MS," Patricia Kennedy said, "because their function is continually changing."



Cinda Hugos makes sure she sees her patients once or twice a year, as needed. "Medicare allows for a reevaluation," she said. "So reassessing their status and updating their home program is appropriate." A key element in those home programs now, she said, is hooking people up with community resources—this yoga class, that aquatherapy group, the other walking club. Often they're the ones offered by chapters of the National MS Society.

Times change … and so do the home plans

Community classes and groups have become a greater part of common practice—a trend toward "empowering people to manage their own problems," Hugos said. She stressed that instructors, whether in yoga or tai chi or Pilates, should be specially trained in the needs of people with MS, even if they're already physical therapists. Many Society chapters already address this need, and more will do so soon.

Other trends include such high-tech solutions as stand-up wheelchairs, robotic assistive devices, and heat extraction, a technique being explored by Dr. Kraft's center at the University of Washington. Research on new approaches, devices, and evaluations of different forms of exercise continue across the country.

At the MS Center of Oregon, the splashiest piece of new research starts where we began: the yoga study that helped Carol Wilkerson. This study compared three groups: Carol's, another group taking an aerobic exercise class, and a third group, still on a waiting list, that served as a control. Neither yoga nor aerobic exercise turned out to have any effect on cognitive function—but both measurably improved energy, mood, and attitude. That study, which is scheduled to be published in **Neurology** this fall, has a living exemplar in Carol Wilkerson.

"Before, I was just sort of out there in the dark," she said. "Now, while my balance is sometimes shaky, through practicing certain balance-oriented yoga poses, I am becoming more sure-footed—like a deer." ■

Chris Lombardi, a freelance writer with MS, is a frequent contributor to this magazine.