

n the 11 years since her MS diagnosis, Eileen Helfand has rarely been inspired to give thank-you gifts to medical personnel: her spastic legs and hands have had her in too much pain. But that's changed. This summer, she found herself buying Lynn Roulette, OTR, some jars of her favorite fresh California jam. Roulette is an occupational therapist who works in the clinic of Michael Berlly, MD, chair and medical director of the Rehabilitation Department at the Santa Clara Valley Medical Center. She's also been Eileen's coach for the past two years.

Occupational therapy—along with physical and speech therapy—is part of the larger process called **rehabilitation**: the ongoing coaching that can help a person with MS, or any other challenging illness, stay on top of his or her game. (See page 38 for news about a major statement on rehabilitation issued by the National MS Society in 2004.)

"I prescribe physical therapy for range of motion, spasticity control, and gait problems," Dr. Berlly said. "Speech therapy is used for cognitive retraining and swallowing evaluations. I prescribe occupational therapy for almost everything else." He introduced Eileen Helfand to Roulette the day she came to his clinic.

Occupational therapists (or OTs) help assess and manage "activities of daily living": that's everything from brushing your teeth to driving. OTs are the first line of defense against the fatigue that impacts over 80% of people with MS. And OTs are often the first medical professionals to hear when someone is affected by the changing nature of the illness.

"When something new comes up, people with MS tend to tell their OT first," Dr. Berlly said. A person's relationship with an OT tends to be fairly personal.

"Being able to look at the whole spectrum of what a person does puts us in a unique position," said Nancy A. Lowenstein, MS, OTR, BCN, clinical assistant professor at Boston University's Sargent College of Health and Rehabilitation Sciences.

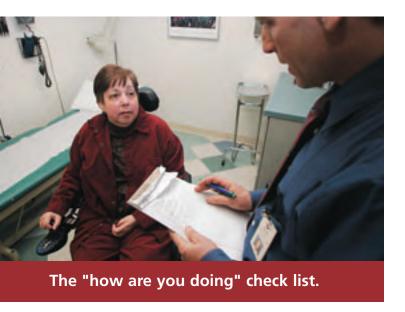


Physical medicine & rehabilitation physician Eddy Chan shows Helfand a finger exercise.

Theodosia "Teddy" Kelsey, OTR, FAOTA, who has been working with people with MS for over 35 years, sees the OT as a "top problem solver," collaborating with people to address "whatever they need and want to do."

A lifelong relationship begins with a conversation

At the beginning of an OT evaluation, the main questions are: What is this person actually able to do? How much help do



they need? To answer these questions, the OT may do a series of tests. But even more important is asking the right questions.

"I use narrative," Dr. Berlly said. He described eliciting people's stories about their daily activities, one by one. Then he tests coordination, strength, and energy. Dr. Berlly uses a 0–5 motor scale in assessing strength, and "I also note how rapidly a person fatigues." All this enters into the narrative.

Teddy Kelsey always starts by asking: What's the one thing that frustrates you the most? After what she calls a "troubleshooting" session, she'll ask another series of questions. "There are problems or challenges a person might not think about until you ask," Kelsey said. Many OTs agree: Persistent questioning, if done right, gives the most accurate picture of the challenges a person with MS is facing.

The more experience a practitioner has with MS, of course, the more he or she will know what to ask. Nancy Mazonson, OTR, who practices in the Boston area, says it's also often a matter of asking **enough** questions. "Some people have been coping with this disease for so long," she said, that what

might, to an individual, be "no big deal" throws up red flags to an OT. A person might think that 3–4 falls a week, or fainting once a day, is just part of the process. The OT is likely to think it requires attention, and perhaps medical evaluation.

One of Mazonson's patients told her that urinary issues were not of primary concern, but on further questioning, "I find out he's transferring 25 times a day from his wheelchair [to the toilet]," Mazonson said.

Thus, the OT evaluation often yields referrals. This man needed a urologist to tame his bladder problems. Others need nurses for symptom management, neuropsychologists for cognitive issues, or speech/language professionals for speech difficulties.

The OT assessment is not complete, however, until the therapist has visited the person's home and workplace. "Maybe they haven't mentioned all the rugs everywhere when they mention falling," Kelsey said. Knowing the specific challenges at hand can ensure that the rehabilitation plan makes sense for the person.

The plan

After assessment, the OT and the client develop a plan together. It will likely include:

- energy conservation strategies, to enable the person to enjoy expending energy on what is most important to him or her:
- exercises, to prevent deconditioning and compensate for damaged nerves; and
- **adaptations** in the home and work environment.

Energy: the most precious resource

Whenever she talks to a newly diagnosed client, Kelsey starts with energy conservation. In MS, she emphasizes, the moment you feel yourself starting to fatigue, you have to rest. "It's really about teaching people to deal with the effects of the disease," Kelsey said. Dr. Berlly concurred. "I want to teach my patients strategies, to look at how they plan their activities, how their home is arranged," he said. "How cluttered is their house? Their calendar? How much time do they spend just getting together the things they need for a task?"

"People desperately want to keep doing what they've been doing all along," Nancy Mazonson said. Only over time can she introduce some of the strategies for conserving energy, like using a mobility aid. She may say, remember how you fell? "There's a big

PT assistant Cindy Salazar demonstrates weight bearing for spasticity management for Lloyd Olmstead.

emotional piece to any lifestyle change," Mazonson pointed out.

Lifestyle change can be more fluid in partnership with an OT. The OT not only understands good strategies to try, but also knows what kinds of community and financial resources can make them happen.

Exercising your arms, your brain, and your mind

Upper-body retraining. "Rehabilitation is not just compensatory," said Mindy Aisen, MD, of the Veterans Administration (VA) and former director of Rehabilitaton Research for Cornell University's Burke Rehabilitation Hospital. While it's important to conserve energy and rest when necessary, it's absolutely possible to recover some function. "Upper-extremity therapies work," Dr. Aisen said.

Rhythmic movements, finger-tapping, even video games are being used by some

MS centers. OTs may also splint some portion of a weak arm to help train the unaffected muscles. And new techniques are always being researched by the VA and others. These include electrical stimulation of bladder functions and deep brain stimulation to control tremor.

Stretching. When Eileen Helfand was first referred to Dr. Berlly, they immediately put together a set of stretching exercises to ease the stiffness and spasticity that affected nearly all her muscles. When her husband, a retired physicist and her full-time care partner, learned how to stretch her, it made ordinary tasks much easier. Stretching can also reduce the stress



OT Renee Coates tests Charlie Hart's grip strength . . .

that makes MS so difficult to cope with.

Cognitive strategies. Memory, processing, and attention problems can affect everything from work to home tasks to driving—with potentially lethal results. Susan Lillie, OTR, CDRS, director of the Adaptive Driving Program at Santa Clara Valley Medical Center, works to see if errors of inattention can be corrected: "We ask people to introduce a new driving behavior" amid the multiple stimuli of the road. OTs will practice being "active passengers" in the back seat: "We'll play a little game, Who sees it turn to red first?" Other OTs will work with people on somewhat more conventional memory jolts: lists, flashcards, prominently posted calendars.

Adapting your environment

"Many people don't realize how much can be done to make life safer and easier," Lowenstein said. Some changes are expensive, others not at all. A few of the many possible changes to the rooms in which we spend our lives include: The office. Would you benefit from an adaptive keyboard? Voice-recognition software? Different furniture? OTs can make recommendations, refer you to manufacturers, and advocate for the changes with your employer. Kelsey says she's often been part of official negotiations between employers, rehabilitation agencies, and her clients.

The kitchen. Changes can be simple, like a one-handed can opener, or more comprehensive. "I'm a big fan of a stool, so you can sit down and cook," Kelsey said. "And reachers, so you don't have to stand up so much." Add a wheeled cart, to move supplies and meals around, and other redesigned gadgets like a one-handed salad spinner or elbowlength oven mitts. The kitchen itself can also be changed: A pullout drawer can be turned into a cutting board. Cabinet doors under the sink can be removed, making sitting at the sink possible.



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The bathroom. When Lynn Roulette came to Helfand's house, they focused a lot of attention on the bathroom. "Lynn gave me some tips on showering and dressing. Later we had the shower remodeled, enlarging it to fit a shower wheel-chair and adding a shower board to make transfers easier." A shower massage, like the one many people buy just as a treat, can help conserve energy. So can a bench. Grab bars, now available in all sorts of attractive colors and designs, can help a person who can stand, but who wobbles.

The rest of the house. Getting rid of throw rugs isn't expensive. Nor are plugin night lights. Simple transfer boards, to help people in and out of bed, and more grab bars might prove valuable. Addressing clutter is crucial.

More extensive changes include widening doorways to accommodate wheelchairs; installing handrails in hallways; making half-height steps; adding a mechanical stair-lift. Marlene Weiner, OTR, founder of Interiors for Independence, a company that develops such modifications, emphasizes that handrails and grab bars are now "very attractive. They are not like the ones you see in the hospital."

In the car. At every appointment, Mazonson asks: "Did you drive here?" If the person answers yes, she then does a series of tests to see if the driving may have been affected by the person's fatigue, weakness, lack of peripheral vision, or cognitive issues.

"Depending on the deficits, a simple change in the brake might be enough to make driving safer," Susan Lillie, OTR, said. "If not, we go to full hand controls.

If the driver's in a wheelchair and needs to transfer frequently, then we go to a van that's been adapted to admit a wheelchair and a ramp. And sometimes a person has to let driving go."

Helfand, whose vision has deteriorated over the years, made the decision last year. "It's not safe for me to drive," she said. She now depends on her hus-



Adaptive devices—like this long-handled shoe horn—preserve independence.

band and on the local para-transit agency: "But for para-transit, you have to make an appointment two days in advance. It's not convenient."

Lillie favors a new trend called "volunteer drivers," pioneered by agencies around the world, in which a core of community volunteers offer to drive those who can't do so. Lillie cited the Beverly Foundation, a senior transportation organization in Orange County, Cal-

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Independence includes pet care. Candy Stoddard gets tips on grooming Hershey.

ifornia, which started PasRide (Pals and Seniors Ride). Numerous senior agencies from Alabama to British Columbia have similar programs. The Independent Transit Network in Portland, Maine, uses automobiles and both paid and volunteer drivers to provide door-to-door service, 7 days a week, 24 hours a day, according to their Web site. People who use the service open accounts and pay for their rides by the mile.

For some, the ultimate solution involves moving to live in areas where driving is less necessary, such as major cities or small towns.

How often? Who pays?

How often should a person with MS be re-evaluated by an OT? Dr. Berlly stresses that this varies widely with each person based upon their symptoms and rate of

progression. He recommends: "A physiatry visit every 3–5 months, at which time the need will be determined for additional OT. As a general rule, OT re-evaluations are needed biannually. If a physiatrist is not available, OT re-evaluations may be needed more frequently."

The National MS Society has just issued a new "Expert Opinion Paper on Rehabilitation", which states among its recommendations:

- The complex interaction of motor, sensory, cognitive, functional, and affective impairments, in an unpredictable, progressive, and fluctuating disease such as MS, requires periodic reassessment, monitoring, and rehabilitative interventions.
- Third-party payers should cover appropriate and individualized restorative and maintenance rehabilitation services for people with MS.

This is in opposition to the position taken by Medicare and, by extension, private insurers, which have tended to require "evidence of improvement." However, none of the clinicians interviewed reported much trouble being reimbursed by Medicare. The 2003 Medicare legislation lifted the annual limits on the number of OT sessions—although the cap is slated to be restored in 2006.

A change is in the air

According to Christina A. Metzler, chief Public Affairs officer for the American Occupational Therapy Association, "More insurers are beginning to recognize that reducing the rate of decline is justification enough for the therapy."

Insurers will usually cover follow-up evaluations a few months after an initial evaluation, although "constant, ongoing OT is not usual."

Metzler added, "Private insurance plans still tend to cover a set number of sessions per year. Sometimes that's for both OT and PT." Many states have mandates that guarantee or limit people to a certain number of sessions annually.



PT assistant Cindy Salazar shows Lloyd Olmstead how to safely transfer in and out of the shower.

Each client, as well as each OT, needs to research the policies of his or her state.

Some important elements may still fall through the cracks. Adapting an automobile is usually not covered by Medicare nor private insurance companies, and neither is a thorough driving assessment, like the one at Santa Clara Valley Medical Center.

The record is also mixed on home

renovations. Most of the simplest adaptations—such as reachers, stools, a bath bench—are not covered by Medicare, although they are often covered by Medicaid. Private insurance coverage varies widely.

Medicare may also balk at covering a device if the patient once had a similar item: Lynn Roulette and Eileen Helfand have been fighting for over a year to get

Helfand's wheelchair covered, because five years ago she had a **scooter**.

There are a few silver linings. Adaptations are tax-deductible. Keep copies of professional recommendations for any challenges by the IRS. There may also be alternative funding sources for major adaptations. State vocational rehabilitation agencies and even job training funds may pay for adaptations that can help a person stay functional and employable. Major vehicle manufacturers have rebate programs that will cover some of the cost of retrofitting vehicles, and some state vocational agencies will kick in money to cover the rest. An OT can help identify funding sources and help people with MS apply for them.

Eileen Helfand and Lynn Roulette have appealed to Medicare for the power wheelchair, backed with extra documentation from Dr. Berlly. Helfand is optimistic that this time they'll be successful. "I thank God every day for Lynn and Dr. Berlly," she said. "I know that if I need anything, I can give them a call."

Chris Lombardi is a frequent contributor to this magazine.

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