

# Taking the next step



## When and how to transition to a mobility device

by Maureen Salamon

During a physical therapy session four years ago, Liz Ripley's therapist handed her a ski pole and told her to walk around the room. Immediately, the Detroit-area woman, diagnosed with primary progressive multiple sclerosis 26 years ago at age 28, noticed she no longer needed to cling to the walls for stability. The walls, she admits, had served as a "crutch" of sorts that helped her get around, but the process of moving about while using them "was just getting uglier and uglier, as well as less safe."

Ripley's physical therapist had deftly made her point: Ripley needed a mobility device, and a cane was recommended. But Ripley wavered for months between denial, sadness and anger before she finally purchased a travel cane—and later, a pair of trekking poles similar to those used by hikers—and realized how much confidence they added to her day-to-day life.

"It gives me more freedom and makes me feel safer and less limited," explains Ripley, now 54. "I decided that I wanted to accomplish something and no longer be hindered."

### Coming to terms

Ripley's experience exemplifies the push-pull of emotional and physical issues that can surround walking as MS progresses.

Needing to use a mobility device for the first time—or transitioning to one providing a higher level of assistance—is often seen as an unpleasant rite of passage, offering physical proof that strength, endurance, balance or coordination is diminishing.

But, as Ripley pointed out, having the right mobility device can actually increase a person's freedom. Ripley says that once she started using a cane, she was able to shop even at big-box stores—previously off-limits for her because the mere act of walking from the parking lot to the store was too difficult. And for some, the need to use an aid such as a cane, walker, forearm crutches (also known as Euro, Canadian or Lofstrand crutches), a wheelchair or a scooter may be only temporary or intermittent—for example, during flare-ups, while traveling, or at certain times of the day.

About one-third of individuals with MS report using a mobility device at least some of the time, according to a large-scale study by Harris Interactive done on behalf of the National MS Society in 2011. And a whopping 92 percent of those who used one said it was worth it in order to live their lives. But the misgivings these devices may provoke can cause some people to dismiss them, or delay making the transition.

"People wonder, 'Am I giving in to MS? Should I fight it more? Am I becoming dependent?' It's a concrete indicator that the disease is worsening, and that's a tough one," says Peggy Crawford, PhD, a clinical psychologist based in Brunswick, Maine, who's worked extensively with people with MS for more than 25 years.

"People also worry about how others will perceive them; they worry about embarrassment and if the device will call attention to them," Dr. Crawford adds. "But they're not worrying about how their current walking is calling attention to them."

### **Making the change**

Indeed, others' obvious curiosity or distress about your walking abilities may be a clue that it's time to consider a new or different mobility device. While physical therapist Amanda Rohrig notes that there's no universal checklist of signs indicating that a transition is necessary, there are some common experiences that might indicate a need for assessment.

These include experiencing an exacerbation that noticeably hampers your ability to move about unassisted, hesitating to participate in activities, or feeling that your world is restricted.

"If MS is preventing you from doing activities at home or engaging in the community, then it is likely time to consider a mobility device," says Rohrig, who works with individuals with MS at Horizon Rehabilitation Centers in Omaha, Nebraska. "Sometimes it's easier [to accept a device] if the need is temporary."

A good example, Rohrig says, is someone with MS who works full-time and then hits a "wall" of fatigue and weakness in late afternoon—choosing, as a result, not to play cards with friends or go out to dinner with her spouse. "A cane or scooter in the evening or earlier in the day may allow her to manage her symptoms more easily and enjoy her life," Rohrig says.

Fatigue alone—experienced regularly by about 80 percent of those with MS—can be a huge red flag that a new or higher-level mobility device is called for, Dr. Crawford notes.

“People underestimate how much of their fatigue is related to not using a specific device,” Dr. Crawford says. “Often they’re putting a lot of effort and energy into trying to remain in an upright status and already using other things as assistive devices, such as walls, furniture or the arms of other people. I think when people put themselves in jeopardy, when they’re falling or getting injured, they may be overdue for some device.”

### **The right device**

Once you and your healthcare team have agreed that it’s time for a new or different mobility aid, it’s important to get the right device—and the right fit. Fit is driven by a person’s height and weight, Rohrig says, while device selection depends on where and how the device will be used.

For example, a cane may work for someone who needs to walk only short distances, but a walker may be a better choice for a person who needs to navigate longer distances.

Rohrig recommends consulting a physical therapist (PT) or occupational therapist (OT) with MS expertise to determine the best options for you in various situations, then trying those options in the clinic and at home before your PT customizes the fit for you. Devices offered at drugstores or medical supply stores are “likely not all of the options available and certainly may not be the best option,” she says. “Furthermore, a PT or OT will size the device appropriately and train you on the proper use in a variety of environments.”

An alternative is to visit an assistive technology clinic. Such specialty clinics are often located in rehabilitation centers and outpatient clinics, where teams of assistive technology professionals—including PTs, OTs, physicians and rehabilitation engineers— can collaborate on the best individualized solution, including customized fitting and training in safely using the device.

Health insurance often covers walking devices, especially lower-priced canes or walkers—along with the training to use them—when prescribed by a physician, Rohrig notes. But some plans may require people to pay out of pocket.

For that reason, she strongly advises people to check their plans before purchasing any durable medical equipment, or consulting with assistive technology professionals. She adds, “If cost is a barrier, consider asking local, nonprofit medical equipment organizations, as well as the National MS Society, for assistance.” Some community resources have “closets” of gently used mobility devices, which they can provide at little or no cost, she says. In addition, the Society can work with individuals to identify other financial resources that may offset device costs.

### **Maximizing mobility**

Gil Greenman, 48, who was diagnosed with MS in 1994, is no stranger to mobility devices. He bought his first cane in 2007 and purchased a wheelchair about a year ago, which he primarily uses for travel. But increasing difficulty getting around convinced him to visit an OT

last winter.

The Seattle resident emerged from the OT consultation with adjustable Euro crutches, offering him far more stability than his cane and making him wonder why he initially hesitated to upgrade his equipment.

“I don’t know why some people have such a block,” Greenman says. “They may see it as the first step toward the end of walking, but for me it felt like a step to more walking, not less.”

“I wish I had begun walking with them earlier,” he says.

**Maureen Salamon is a New Jersey-based writer.**

For more information, download [Choosing the Mobility Device that’s Right for You](#).

Call an MS Navigator at 1-800-344-4867 for assistance in finding a physical therapist or in exploring possible sources of financial support for mobility aids.