Staying behind the wheel

Driver rehab and vehicle modifications can help some people with MS retain their independence.

by Elise Oberliesen

The day Ann Murray accidentally hit the gas pedal instead of the brake, she knew she'd had a wake-up call she'd never forget. On that day in January 2015, the Cheyenne, Wyoming, resident came face to face with some of the changes that can accompany multiple sclerosis—a diagnosis she'd had since July 1999—and their possible consequences.

For people like Murray, 54, the prospect of turning over their car keys because of MS-related symptoms can create uneasy feelings about the loss of independence. Unfortunately, worsening MS symptoms can render driving too difficult or unsafe for some people—leaving them to make tough decisions.

Options for drivers

Not everyone with worsening MS symptoms will have to put the brakes on driving altogether, though. If you're concerned about your safety, you can put your road skills to the test with a certified driver rehabilitation specialist (CDRS), a professional—usually an occupational therapist—who evaluates both your driving skills and physical abilities.

The MS symptoms that most commonly interfere with driving include tingling and numbness in the limbs, muscle weakness, spasticity, cognitive changes, blurred or double vision, poor coordination and fatigue. These can affect a person's ability to use the gas pedal, brake, steering wheel, gear shifter and so on; they can also affect an individual's ability to judge distances, pay attention to multiple factors simultaneously, make rapid decisions and

respond quickly.

After the evaluation, the CDRS can make recommendations for further training or adaptive equipment, such as hand controls for the gas and brakes, or a spinner knob for the steering wheel, says Elizabeth Green, executive director of the Association for Driver Rehabilitation Specialists (also known as ADED, the acronym for its former name), a nonprofit organization that certifies the driving specialists.

A roadmap for rehab

Even though Murray's driving mishap caused no damage or injuries, she wondered when she'd have a "real" accident—which is why she wasted no time asking her neurologist for a referral to a driving rehabilitation program. She made an appointment with a CDRS and completed the driving program in six weeks.

Murray had considered a driving rehabilitation program before her near miss, but like most people, she thought she was still doing OK—until that day, when she recognized that her leg spasticity made it too difficult to reliably control the gas and brake pedals safely. "If I wanted to continue to live independently, I knew I had to learn to drive with hand controls," she says.

Modifications make a difference

Modifications can make a big difference for drivers with MS.

Modifications include hand controls for the gas and brakes.

An adaptive spinner knob can help with steering (above and below).

Photos by Riku Foto

Maintaining independence is the primary motivator for most people who enroll in a driving rehab program, says Patrick Baker, MHS, an occupational therapist (OT) and CDRS at the Driving Evaluation and Rehabilitation Program at the Cleveland Clinic.

It was certainly true for Sandy Wittenberg, who was diagnosed with MS in August 1994. The now-51-year-old from Clermont, Florida, started driving with hand controls in 1998. She says the freedom of driving was something she wasn't willing to give up. When she learned that a CDRS could teach her new driving strategies and that she might qualify for vehicle

modifications, she eagerly signed up.

While vehicle modifications can certainly be a primary component of a driving rehabilitation program, there's more to it. You need a doctor's referral and a valid driver's license, which "may need to be temporarily changed to a rehabilitation permit for the training," depending on the state, says Christy Dittmar, an OT and CDRS, as well as the clinical director of the Center for Neurorehabilitation Services in Fort Collins, Colorado. Driving rehabilitation programs generally consist of the following four components.

1. **Clinical evaluation.** An OT assesses an individual's vision, cognition, range of motion, strength and reaction time—all critical aspects of safe driving, says Baker.
2. **Referrals for additional assistance.** If Baker spots visual, cognitive or physical limitations during the evaluation, he refers people to specialists. About 25 percent of drivers receive referrals, he says. Say a person demonstrates reduced strength, for example, in her core muscles, which could make it difficult to sit upright while driving. Baker would send her to a physical or occupational therapist; with cognitive concerns, to an OT or a speech-language pathologist; and with concerns regarding vision, to a neuro-ophthalmologist. These specialists can establish a rehabilitation program to address these challenges and help develop adaptive strategies.
3. **Driving evaluation and training.** In this part of the program, a CDRS can assess how well drivers do during actual time behind the wheel, and can acquaint drivers with adaptive controls in the car, if needed. "Based on that information, we work with the individual to develop a plan for equipment and further training, if necessary," Dittmar says.Green says some drivers might only require suggestions aimed at optimizing their driving skills, however. "They might benefit from adapted driving strategies and behaviors to help manage fatigue, weakness or cognitive challenges throughout the day. We might help them with route changes or ways to conserve energy, such as running one errand at a time, or driving when they have the most energy," she says.Murray described her first instructor-led driving session as an icebreaker where she familiarized herself with hand controls in a quiet neighborhood. In following sessions, she ventured into traffic on main roads, working her way up to rush-hour traffic before braving the interstate.

   Wittenberg recalled feeling tired after her first two-hour driving session. She was surprised at the amount of arm strength she needed to work the hand controls and how easily she became fatigued. But she persisted, within her abilities. "In less than a week, I was used to driving with hand controls," she says.

   When drivers do experience MS fatigue, Baker tends to shorten driving sessions. If the fatigue is related to muscle weakness, he offers specific exercises designed to strengthen the muscles used for driving. "Sometimes they need to work with another OT to strengthen their core, shoulder or upper arm," says Baker.

   Expect about four to six adaptive driving sessions, lasting one to two hours each time,

say Dittmar and Baker.

4. **Vehicle modification.** Based on the recommendations made during their evaluation, drivers will receive a "prescription" from their CDRS for the specific equipment needed. This prescription will include additional information for the mechanic, such as the make and model of their car and installation instructions, says Dittmar. Then, the CDRS generally helps identify a certified National Mobility Equipment Dealers Association mechanic to install the equipment. (To locate a dealer, visit nmeda.com/locate-dealer.)

Murray had an adaptive spinner knob installed for steering assistance, along with gas and brake hand controls. The equipment can go beyond hand controls, however. Wittenberg says she now uses an OT-recommended chest strap to help hold her upright while driving. Extra mirrors and remote switches to control radio, windshield wipers or air conditioning are among the many other options.

Baker says insurance companies currently do not pay for the driving program, equipment or its installation on personal vehicles. But some car manufacturers offer rebates when customers have adaptive equipment installed on new vehicles. For example, "Ford Motor Co. offered me a $1,000 rebate," says Murray. After the rebate, her out-of-pocket cost was about $500 for equipment and installation on her car, and approximately $500 for her driving rehab program. (For more information on rebates, visit nmeda.com/how-to-buy/rebates.)

Murray says learning to drive with hand controls is one the best decisions she's made. "I wish I had done this when I first started to feel uncomfortable while driving," she says.

Wittenberg is similarly enthusiastic about the program. "Being able to drive means I can go out to dinner with friends, go to work, go to my nephew's lacrosse games. Now I don't have to rely on someone to take me," she says. "I live the best life I can."

The road ahead

In some cases, an individual may not pass the evaluation and training with a certified driver rehabilitation specialist, and is no longer considered a safe driver; in such instances, it may be time to retire the car keys.

In making such a decision, it's important to have an open conversation with family and friends to discuss alternative transportation options, so the individual can continue pursuing activities that enrich his or her life. Depending on physical and cognitive abilities, mass transit, such as buses and light rail, which are obliged by law to provide accessible options, may be convenient alternatives. In areas without a robust mass transit system, Baker suggests checking into volunteer ride programs in the community, adding that the Area

Agency on Aging may be a good place to start. MS Navigators at the National MS Society can also help individuals identify transportation support systems.

Whether you learn to drive using adaptive equipment and new strategies, or you make the decision to stop driving altogether, there are plenty of options out there to help you stay moving and mobile.

Elise Oberliesen is a Denver-based freelance writer.

To find a CDRS, search ADED's directory.

To discuss transportation options in your area with an MS Navigator, call 1-800-344-4867.

Download the Society's Driving with MS brochure.