

## Easing into the right seat

by Chris Blöse

The Reverend John Campbell obeys the laws of physics by staying in constant motion. When he isn't delivering a sermon, he might be perusing a craft show or visiting a bed and breakfast with his wife in the hill country of eastern Pennsylvania. Better yet, he might be portraying a wounded soldier in a battlefield reenactment.

Not so long ago, the 61-year-old Civil War buff didn't have to stretch his acting chops too much in those reenactments. He really was exhausted, and he really was in pain. Like many people with MS, he had a seating

With the decrease in sensory messages that comes with MS, having the right fit—for a wheelchair, for a cushion or even for your favorite chair at home or work—becomes crucial for avoiding fatigue, pain and, worst of all, pressure sores.

"In my first two wheelchairs, I would push myself around," Campbell said. "I'd be fatigued within 20 minutes. I'd just be worn out. I'd have to rest. That's not much fun for my wife when we're trying to do things."

John and Sharon Campbell in Gettysburg.



Pain, fatigue and dangerous pressure sores can dog those who spend most of their day sitting. But it doesn't have to be that way, experts say.

To get exactly what you need, medical professionals recommend this kind of team approach—through professional seating clinics, if possible. The reason? Customization. No single cushion, chair or other assistive technology product is right for every person, said Beth

Gibson, a PT in Tucson, Ariz.

Kathleen Senge, 59, discovered this the hard way. The Pennsylvania resident used a power scooter during a trip to Disney World with her grandkids. Getting out of the chair was difficult and asking for help no fun at all, so she stayed put too long and developed a pressure sore from the hard leather seat. She sought medical care—always the right

Over the years, Campbell has found fixes for his problems through consultation and teamwork with his doctor, a physical therapist and a seating technician. When they realized his incorrect pushing technique in his manual wheelchair was causing pain and much-too-quick fatigue, they measured and fitted him for a more ergonomic chair. When a cushion was causing back pain,



An alternating pressure cushion system can be the answer when the risk of pressure sores is high.

AQUILA CORPORATION

ROY HORNE

thing to do if a pressure sore develops—and needed a stay in the hospital to heal it.

Power scooters work well for getting a person from point A to point B, she learned, but they're not necessarily designed for full-time sitting. When she was healed, Senge worked with her medical team to get more appropriate seating. Her new power wheelchair is much more technical than her older ones. "It almost looks like a little airplane cockpit," she said, adding, "I can move the seat as little as a quarter of an inch to be more comfortable."

As Senge discovered, technology has come a long way. Cushions now come in a range of materials and styles, including fluid and air cushions designed to



Tilting power chairs put the user in charge.

distribute weight so that no single part of the body—the buttocks in particular—bears the brunt. Additionally, there are "alternating pressure" cushions that inflate and deflate in certain spots to move pressure points around.

However, no one product is perfect for everyone, repeated Chris Maurer, PT, ATP, a seating specialist and researcher at the Shepherd Center in Atlanta. For example, for some people,

alternating pressure cushions may create too much pressure on certain points even as they alleviate pressure on others. The key is finding appropriate advice on products and then getting the instruction needed to use the products properly. Maintenance is a constant issue—keeping batteries charged, making sure the cushion fits the chair, and so on.

Maurer praised modern power wheelchairs for what they do in terms of positioning. They can tilt backward up to 55 degrees and/or recline to take pressure off the buttocks to assist in pressure ulcer prevention. Powered seating systems can also be used in small increments to help manage pain or improve comfort. "The user is in charge," Maurer said.

The user is also in charge of working with the right people to find the right seating—whether it's a favorite comfy chair at home, an ergonomic office chair, or an electric wheelchair.

"Chairs are like shoes," Gibson concluded. "They need to fit the person."

For information on wheelchairs, cushions and other assistive technology, visit [abledata.com](http://abledata.com). To find a certified assistive technology professional, visit [resna.org](http://resna.org). And for referrals to physical therapists and seating clinics in your area, call 1-800-344-4867 and ask for an MS Navigator™.

Chris Blose is a freelance health writer.

## Exercise also has to fit

People's capabilities change over time, but one thing remains the same: A daily exercise regimen is crucial for people with MS whatever their mobility level. Working on posture and core strength every day—from the day of diagnosis onward—can help prevent some seating issues from ever occurring in the first place. Moreover, establishing exercise habits early on can help people stay mobile longer.

For posture and core strength, yoga typically works well, as does general stretching. Gibson is the author of **Stretching for People with MS** ([nationalMSsociety.org/Stretching](http://nationalMSsociety.org/Stretching)) and **Stretching with a Helper for People with MS** ([nationalMSsociety.org/StretchingHelp](http://nationalMSsociety.org/StretchingHelp)).

"My line is this: If it moves, move it. If it used to move, move it more!" Gibson said. There are stretches people can do using a cane, a coffee table, a bed, a chair or wall, she points out. Ask your health-care provider for a prescription for physical therapy and learn what fits you best. —CB

## Who can help the helpers?

by Greta Herron and Patricia Wadsley

Here's a roundup of resources.



**An MS Navigator™** is on hand at the Society chapter nearest you, to help family caregivers find appropriate local resources, including support groups, social services, respite care, and other voluntary organizations. Call **1-800-344-4867!**

**The Family Caregiver Alliance** was the first community-based nonprofit organization in the country to address the needs of families and friends who provide long-term care at home. FCA offers a wide range of national, state and local programs. **caregiver.org**

**The Well Spouse Association** supports spousal caregivers. Services include a quarterly newsletter, online mentorships, Web forums, local peer groups and more. **wellspouse.org**

**Lotsa Helping Hands** is a free national online service for family and friends to use as a personal clearinghouse for an individual's care network. One volunteer does the work of posting what needs to be done for that person, including transportation and schedules of coverage. The volunteer also sets up automatic reminder e-mails and updates for the network of friends and family members. **lotsahelpinghands.com**

**National Alliance for Caregiving** is a national advocacy organization that conducts research, develops policies and programs, and works to strengthen state and local caregiving coalitions. It publishes some helpful brochures for family caregivers and maintains the Family Care Resource Center, which has reviews and ratings for hundreds of books, videos, Web sites and other materials on caregiving. **caregiving.org**

**National Caregivers Library** is a Web-based collection containing hundreds of articles, forms, checklists, tools and links to topic-specific resources. **www.caregiverslibrary.org**

**Disabilityinfo.gov** is an award-winning federal government site designed as a source of information on a host of disability-related programs and services. The site includes a state and local resources map for finding disability-related information in specific areas.

**Caring Connections** provides free resources, information and motivation for learning about end-of-life issues. The site includes links to each state's advance directives requirements and to the National

Hospice Palliation Care Organization for more resources on planning, decision making, grief, hospice care, and other end-of-life matters. **carinfo.org**

**Caring Bridge** is a free site that updates a network of personal supporters about an individual's ongoing health status, treatments, therapies, and recovery. A family member can keep friends and relatives informed during difficult times and in return they can leave personal guestbook messages. **caringbridge.org**

**American Association of Retired People (AARP)** has a free caregiving planner and a number of helpful tools for calculating needs and resources. **AARP.org/family/caregiving**

### On the newsstand

**Caring Today** is a bi-monthly magazine and Web site providing practical advice about home care for many chronic diseases and conditions. Subscriptions start at \$15.95/year if you sign up on the Web site. **caringtoday.com**

**Today's Caregiver** magazine, published bimonthly by Caregivers Media Group, provides information, support and guidance about many diseases and conditions to professional and family caregivers. \$18/year **caregiver.com** ■

Greta Herron and Patricia Wadsley are on staff at **Momentum**.