Bringing exercise home



Even people with progressive MS can reap the benefits of exercise by working with specialists to develop home-based programs.

by Vicky Uhland



Shelley Peterman
Schwarz has primaryprogressive MS but
makes time most days to
do range-of-motion
exercises. Photo courtesy

Shelley Peterman Schwarz has lived with primary-progressive multiple sclerosis since at least 1979, when she was diagnosed. While in recent years the progression of her disease has stabilized, she still has no use of her legs and minimal use of her arms and hands. If anyone has an excuse not to exercise, it's Schwarz.

And yet, this retired schoolteacher; author of seven books, including **Multiple Sclerosis: 300 Tips for Making Life Easier**; and motivational speaker makes time most days to do a series of range-of-motion exercises in her Madison, Wisconsin, home.

"I realized long ago that exercise was probably the most important thing I could do for myself as my disease progressed," Schwarz says. "Exercise gives me the strength to reposition myself in my wheelchair, to put on a T-shirt, to lift a hanger. By anyone's standards, these are tiny, tiny things, but in terms of my self-esteem, they are huge. They help make me more independent."

Home-based exercise doesn't only help individuals like Schwarz. "All people with MS may benefit from home-based exercise programs, regardless of the stage or course of the disease," says Amanda Rohrig, a physical therapist with Horizon Rehabilitation Centers in Omaha, Nebraska. "For example, people at an earlier stage in their disease or with a mild disease course who generally exercise at a gym may appreciate the home-exercise option for days when they are experiencing more fatigue or have limited time."



Tonya Thompson, who augments gym workouts with her rowing machine, says her MS symptoms became less severe after she started working out last year. Photo courtesy of

Tonya Thompson

prone to falls.

Take Tonya Thompson, for example. Thompson was diagnosed with MS in 2009. Fatigue and balance issues caused her to stop working out until last year, when she realized her quality of life had severely declined. So she decided to start exercising again. "I thought, 'I need to be as successful and healthy as I can be, and this is how I do it,' " she says.

Thompson augments gym workouts with sessions on her rowing machine at home. She practices her balance by grabbing 5-pound weights and walking down her tiled hallway without stepping on any grout lines. Within two months of starting this exercise routine, Thompson saw not only physical benefits, but emotional ones as well. "I have a whole new outlook on everything—more self-esteem, extra energy and better balance. I can bend over and pick up things without falling," she says. "And I lost 20 pounds!" There are reams of research showing that exercise helps increase stamina and strength, improves mood and may boost cognitive performance in people with MS. Furthermore, two small studies found that men and women with MS who did resistance training at home three times a week for eight to 12 weeks had more balance, power and mobility, and were less

"The reality is that any muscle movement is a good thing for people with MS," says Alexander Ng, PhD, an associate professor in Marquette University's exercise science program. "Nothing says you have to do high-intensity exercise in a gym to improve your health."

Bonus: Momentum fitness card

Fitness Card

Parallel 10 (10 to 10 to 10

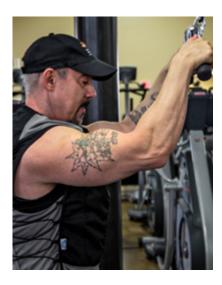
<u>Download and print</u> this handy form to take to your physician, physical therapist or other exercise specialist, and discuss any movement challenges you may be having.

Home exercise has other advantages as well. It's convenient, especially for people with transportation issues. It eliminates the fatigue associated with preparing to leave home or putting on workout clothes. Plus, it can be less expensive than joining a gym or health club. But because it's often not supervised by an exercise professional, it can create safety issues. And motivation can be a problem when your workout space is also home to a comfy couch and a remote-controlled TV.

Fortunately, there are plenty of ways to overcome these issues. Turn the page to learn how to start your own home-based exercise program.

Make it personal

Virtually any gym-based exercise can be adapted for home use, no matter what your level of fitness and disease progression. "People with MS can do cardiovascular, strength, flexibility, balance and breathing exercises all at home," Rohrig says.



David Lyons is a bodybuilder who adapted his fitness routine to accommodate his MS symptoms. Photo courtesy of David Lyons

But it's important that any exercise you choose be individualized for your specific symptoms, says David Lyons, a Murietta, California-based fitness expert, former health club owner and public relations director/MS advocate for Gold's Gym in El Paso, Texas. Lyons, who was diagnosed with MS in 2006, is the founder of the MS Fitness Challenge, a 12-week program conducted at locations around the country (for more details, visit msfitnesschallenge.com). He's also a bodybuilder who has learned to adapt his fitness routine to accommodate symptoms like numbness, pain and tingling on his left side; foot drag; lack of grip strength in his left hand; and optic neuritis.

"With MS, everybody's symptoms are so different, and every day is a different day," Lyons says. "That's the biggest challenge in developing an exercise program. It has to allow you to work within the level that your body is enabling you to work."

That's why it's key that before you embark on a home-exercise program, you talk with your primary care physician or MS healthcare provider and then consult a physical therapist, clinical exercise physiologist at a healthcare facility or university, or a personal trainer who

works with people with disabilities. This doesn't have to be time-consuming or costly—Dr. Ng recommends one or two beginning sessions with a specialist (which may be covered by insurance), and Rohrig suggests a tune-up visit every six months to adapt your exercises to any changing symptoms. (Find such professionals by contacting an MS Navigator at 1-800-344-4867).

It's also a good idea to discuss any workout tools or exercise videos and books that you'd like to use with your exercise specialist. And you'll want to talk about how frequently you should exercise. Lyons and Dr. Ng recommend some form of movement every day, with longer workouts three to four times a week. Thompson tries to spend a total of 20 minutes exercising each day, spaced throughout the day. Schwarz does 45 minutes to an hour of range-of-motion exercises three to four times a week.

Exercise is fun



Exercise ball

An exercise ball can help to improve balance, and you can use it at home. Bear in mind: Balance exercises need to be individualized to accommodate specific challenges.



Dancing

Dancing is fun and offers a good aerobic workout—wherever you are. If you're less mobile, an exercise specialist can help you design wheelchair dance routines.



Resistance bands

Resistance bands can work the legs as well as the arms, and can provide varying levels of challenge.

Illustrations by Mona Daly

Anything goes—with adaptations

Depending on your symptoms and what types of activities you prefer, your exercise specialist may recommend specific categories of workouts. Rohrig, Lyons and Dr. Ng offer the following adaptations for various types of home-based exercises.

• **Aerobic.** Adaptations to strenuous activities, like Jazzercise or boxing, can be done while seated, giving you the cardiovascular effects with less fatigue, Rohrig says. Tai chi, a Chinese exercise that focuses on slow, gentle and continuous aerobic movement, is a less tiring option, especially if you do it seated. You can also ask your exercise specialist if adapting an aerobics video or a game-based program like Wii Fit will work for you. Several studies have shown that people with MS who use these types of exercise tools may benefit with improvements in balance, strength and gait.

Rowing machines and stationary bikes provide stability and allow you to sit and rest in between cycles of exertion. You can also simply walk around your block or inside your house, using hiking poles if you need help with balance.

Dancing is another fun aerobic activity you can do at home. If you have mobility or balance issues, a dance partner can provide assistance and also help motivate you. Or ask your exercise specialist about wheelchair dance routines, in which you use your upper body to pivot your wheelchair to match your partner's steps.

Dr. Ng conducted a pilot study last year in which ambulatory people with MS did an hour of ballroom dancing twice a week for six to eight weeks, with a partner who didn't have MS. At the end of the study, the participants with MS had improved balance and cognition, less depression and better quality of life. (Read "Social season" for more information on this.)

• **Strength training.** Lyons is a big fan of resistance bands, which can be used in a variety of ways to target individual limbs. You can find the bands in a range of tension levels at sporting goods stores, big-box retailers or online. Lifting mini dumbbells or soup cans can help you build arm strength while seated. Gripping a squishy ball throughout the day can improve hand strength. Modified situps or seated Pilates

exercises can build up your core muscles, which are important for balance and shifting yourself while seated or lying down.

Whichever strengthening routine you choose, remember that it's important to consult with your exercise specialist about the correct way to perform each exercise, the right amount of weight and the proper number of repetitions—especially if you have numbness. Lyons once tore a pectoral muscle while lifting weights because he couldn't feel the painful warning signs.

• **Flexibility.** Stretching exercises are often effective for managing spasticity, Rohrig says. For example, calf stretches can help improve spasticity-related foot drop. For other flexibility exercises, consult the National MS Society brochures, "<u>Stretching for People with MS</u>" or "<u>Stretching with a Helper for People with MS</u>."

Yoga also improves flexibility and has been found in some studies to be beneficial for people with MS.Yoga can be done seated or standing and is easy to do at home, especially if you follow a video. The Society lists recommended books and videos that can help you get started at nationalMSsociety.org/yoga.

Because stretching can sometimes be tedious, Rohrig recommends incorporating it into your daily activities. Prop your leg on a chair while you're watching TV, or do a calf stretch every time you exit the bathroom.

- **Balance.** Rohrig cautions that balance exercises need to be highly individualized to accommodate your balance challenges. She says there are many creative ways to improve balance at home—for instance, you can walk down a hallway while turning your head to look at pictures or various targets on the wall. Scatter pieces of foam or pillows to learn to walk or stand on an uneven surface. Sit on a balance ball or a Dyna Disk balance cushion. A more advanced balance activity may include standing in a corner with your eyes closed, with a chair in front of you for safety. This may help manage a common balance problem—standing in the shower with your eyes closed. Ask your exercise specialist what might work for you.
- **Breathing.** Respiratory muscle weakness is common in people with MS. "Breathing exercises are also a beneficial option for days when MS fatigue is elevated," Rohrig says. She recommends starting out with 10 deep breaths two to three times a day. You can also practice with a spirometer—an inexpensive plastic device available from medical supply stores.
- Range-of-motion exercises. These are also highly individualized and often involve help from a friend or partner. Schwarz consults with her physical therapist about every two years for new exercises and techniques. She makes sure to take a friend with her to learn the exercises. The friend then teaches other friends, and they trade off helping Schwarz with her exercise sessions throughout the week.

Schwarz's range-of-motion exercises include lifting, bending and kicking her legs;

swiveling back and forth and repositioning herself in her wheelchair; pivoting to transfer from her wheelchair to her bed; raising her arms; clapping; pulling cans out of the pantry; helping to set the table; and drying dishes that have been placed in her lap. "The increments of improvement are minimal, but even if it's tiny it feels good," she says.

Risky behavior

Safety is a key consideration when you work out at home. It's important to consult a specialist to make sure you're doing the proper exercises in the correct manner; ideally, it's great to have a friend or family member around, too, to check your form and make sure you don't overtax yourself.

Exercise assistants can provide emotional and spiritual support as well. Schwarz says both she and her helpers enjoy their private sessions, a time when both parties can catch up and talk about their lives. "It's caring on an intimate level, and it shows me that other people's lives aren't perfect either."

If you don't have someone to help monitor your fatigue levels—or even if you do—listen to your body. Schwarz has learned to watch for warning signs that she needs to stop exercising. "If my leg starts to tremble, I know that I shouldn't try to do even one more thing," she says. "And if I start feeling foggy, I know that's my brain saying I'm done."

But what if you haven't been exercising regularly and don't know your body's cues? Lyons recommends starting at a "ridiculously low rate, and when you get used to exercising, increase your movements." Dr. Ng and Rohrig say it's also important to measure your activity level by using the Borg Rating of Perceived Exertion Scale. The scale allows you to evaluate your level of exertion from 0 (no effort) to 10 (maximum effort). Ng and Rohrig both recommend keeping your exertion at whatever feels like a 3 to 5 rating to you while exercising and at a 1 to 2 level while warming up or cooling down. (Learn more about the scale on our downloadable Fitness Card.)

Exercise specialists also suggest using cooling vests, staying hydrated and spreading your activities throughout the day to minimize fatigue as well as heat stress, which can result from a slight increase in core body temperature and cause a temporary worsening of symptoms.

Thompson aims for a mile a day on her rowing machine, which takes her 10 to 12 minutes. Some days she can do it in one sitting, but when she's feeling particularly tired, she might do it in three sessions. "Exercise doesn't have to be sweating until you fall over," she says. "Do a little bit at a time and you'll get there."

Tips to stay motivated

"Many people with chronic conditions, myself included, fall victim to disuse of their muscles, because frankly it is quite difficult to use a tired and hurting body, and the chair or bed seems so inviting instead," says Ofer Agam, a former soldier in the Israeli army who was

diagnosed with MS in 1980 and now has the secondary-progressive form of the disease. (Read more about Agam's story in "The purple parachute.") So how does he motivate himself? "I firmly believe if you use it, you don't lose it," Agam says. "I think I've delayed my disability a whole lot by exercising."

For the days when no motivational speech works, try asking a family member or friend to exercise with you or just hang out in the house while you work out. "That helps me remember that while it's easy to give up, that's not what the people around me want for me," Schwarz says.

Vicky Uhland is a Lafayette, Colorado-based freelance writer and editor.

Learn more about exercise and MS at NationalMSsociety.org/Exercise.

Learn more about how yoga can help create strength and flexibility in "Yoga for MS."