Most people with MS are well aware of how variable and unpredictable MS can be. Some people’s symptoms vary so much from day to day that they start each morning with a little “body check”: How are my legs feeling today? Is my vision better in that eye? Is that arm still numb? How’s my balance? One of the great frustrations of living with this uncertainty is not knowing how to plan for the day, the week, or the month. You may worry about committing yourself to a plan or an activity that you may not be able to handle when the time comes.

One helpful strategy is to develop a “tool chest” of the various types of equipment that help you do the things that are important to you. Whether indoors or out, on the move or at your desk or kitchen sink, there are dozens of assistive devices designed to conserve energy, increase mobility and safety, and enhance function.

Each person’s tool chest is unique, filled with whatever tools are necessary to get the job done. One young father with MS has the trunk of his car filled with mobility aids, including a cane, forearm crutches, a walker, and a lightweight wheelchair. Each day, he would do his body check, look at his list of To-Do’s, and decide what kind of aid(s) he needed to get them done. He was determined that his MS wasn’t going to keep him from getting around and being productive.

A side benefit of this kind of tool chest is that it gives a clear message to others about the variability of MS. Your children will quickly grasp the idea that you feel better and stronger some days more than others, and they will see that you use whichever mobility aid you need to share activities and outings with them.
TIPS FOR HELPING KIDS ADJUST TO NEW MOBILITY AIDS

- Have them choose a name for your cane or scooter or wheelchair.
- Let them try out the device themselves.
- Let them help you decorate your cane with decoupage or make a banner for the back of your wheelchair.
- Let them help with ideas for your “tool chest.”

How can you subscribe to KEEP S‘MYELIN?

Call 1-800-344-4867. Ask to be added to the Keep S’myelin list.

IT’S FREE!
“Will I end up in a wheelchair?” It’s the first question many people ask when told they have MS. The use of any type of mobility device is often viewed as the hallmark of disability, the ultimate sign of defeat. Viewed from a different perspective, however, canes, walkers, motorized scooters, or wheelchairs help people live active lives. They promote independence, conserve energy, and generally make life easier.

Energy is a valuable resource and people with MS can use mobility aids to protect this precious commodity. Devices can get them where they want to go with enough energy to be productive—and have fun—once they get there.

Using a mobility device is seen as “giving in to MS” by some. They are determined to resist any change that would crown MS the winner. Mobility devices can become tools for winning, not giving in. A cane or a rolling walker can prevent falls and control a staggering gait. A scooter can make shopping trips manageable, and visits to a museum or zoo a pleasure instead of a trial. A person might use nothing at all on the best days, and go with a walker when feeling more fatigued. A wheelchair or scooter may even make a new sport possible or reopen the door to an old favorite. People in scooters bowl, fish, and play golf. Others use wheelchairs for tennis or basketball.

Mobility devices allow people to go where they want without having to rely on others. They can keep pace with everyone else, “walk” side-by-side, and share laughter and conversation. Family members, friends, and co-workers no longer find themselves worrying about the person with MS getting hurt in a fall or becoming too tired to stand.

Many people struggle to walk unassisted so others won’t stare, feel sorry for them, or think less of them. In other words, they dread being stigmatized or labeled. It’s worth remembering that mobility devices often help people look less disabled. A person struggling to walk may attract attention.

A person using a cane looks purposeful, and may even give off an aura of confidence. A person sitting comfortably in a power chair keeps up with others and arrives looking (and feeling) in control.

Excerpted from an article by Rosalind Kalb, PhD.
When one member of a family has MS, it is important that the entire family learn about it.

Timmy’s Journey to Understanding MS is an animated cartoon that shares a little boy’s adventure learning about MS. Developed for children ages 5-12, but appropriate for all ages.

To learn more about these and other National MS Society resources contact an MS Navigator® at 1-800-344-4867 (1-800-FIGHT MS) or visit nationalMSsociety.org.

RESOURCES

Plaintalk: A Booklet about MS for Families
Discusses some of the more difficult physical and emotional problems many families face.

Someone You Know has MS: A Book for Families
For children, ages 5-12. A story about Michael and his family explains MS and explores children’s fears and concerns.

When a Parent Has MS: A Teenager’s Guide
For older children and teenagers who have a parent with MS. Discusses real issues brought up by real teenagers.

Keep S’myelin is a publication for children with parents or other relatives with multiple sclerosis. It is produced by the National Multiple Sclerosis Society. The National Multiple Sclerosis Society is proud to be a source of information about multiple sclerosis. Our comments are based on professional advice, published experience and expert opinion, but do not represent therapeutic recommendations or prescriptions. For specific information and advice, consult a qualified physician.

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The National Multiple Sclerosis Society mobilizes people and resources to drive research for a cure and to address the challenges of everyone affected by MS.

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