Multiple Sclerosis
The author and her family on an Alaskan cruise in August 2016.
Multiple Sclerosis
Tips and Strategies for Making Life Easier
Third Edition

Shelley Peterman Schwarz
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A Word From the Author

The world and I have both changed a lot in the 10 years since I wrote the second edition of *Multiple Sclerosis: 300 Tips for Making Life Easier*. Now 10 years older and, I hope, a little wiser, I felt that this NEW book had to go beyond the tips and strategies of the original book. I wanted this book to include more personal, real-life stories and experiences from my 38 years of living with multiple sclerosis (MS).

I also wanted to answer the following important questions (and so many more):

- How do you stay positive and keep motivated when life is no longer under your control and the “rules of the game” keep changing?
- What do you do when family and friends don’t understand what you’re going through?
- How do you stay involved when you’re no longer able to do what you once did?
- How do you bounce back when MS knocks you down, over and over again?
- How do you remain a responsible parent when you don’t have any energy or stamina?

When I started my MS journey in 1979, I didn’t know that I would become severely disabled. (Remember, this was before any of the medications to treat MS were developed. And, because of my primary progressive MS diagnosis, I never qualified for the treatments that were developed.)
In the beginning, I lost physical abilities every day. I tried to keep up and find new ways of doing things. I’ve always been a positive person and a lifelong problem solver, but the daily struggles were a real test to my ingenuity. I had to find ways of consolidating, streamlining, and rearranging the way I did simple everyday tasks. Each time I have faced a problem that MS imposed, such as dressing myself independently, I took it as a personal challenge.

I began developing my own tips, techniques, and time-savers and soon realized that everyone has his or her own ideas for making life easier. I became a keen observer of how other people did things. Even today I look at obstacles and inabilities as problems waiting for a solution. After years of all sorts of personal and professional challenges, I have discovered that I can be quite creative and resourceful. There are not many things I “can’t” do, and I hope you will find this, too.

What I also learned was that my attitude and outlook were even more important to my well-being than all the tips and time-savers. I had to adapt and develop new skills and strategies to handle everyday situations that made me feel sad, frustrated, lonely, and that diminished my self-worth.

When you have MS, you never forget that you are living with a chronic, progressively disabling disease. Yet, despite all the challenges, I’m happier now than I have ever been before, and I live a remarkably unlimited life. I hope the ideas and information in the book encourage and inspire you to make yourself a priority and do the things you need to do to be happy and enjoy life.

In the not-too-distant future, medical science will find a cure for MS and we owe it to ourselves to be in the best mental and physical shape possible when that day comes.

I leave you with the words I live by . . .

When you live with love and gratitude in your heart, you transform yourself and the people around you!

I wish you the best on your journey,

Shelley Peterman Schwarz
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To all my wonderful friends and neighbors: Please know that I couldn’t do what I do without you, and you have my deepest, heartfelt thanks.
Multiple Sclerosis
Share

Multiple Scleroris: Tips and Strategies for Making Life Easier, Third Edition
CHAPTER 1

Basic Principles for Living With MS

Being diagnosed with MS forced me to simplify my life. I was 32 years old, and it was clear that life as I knew it had changed forever. As much as I wanted to deny it, I could not physically, mentally, or emotionally keep up the break-neck pace I demanded of myself. Over the years, I realized there were several basic concepts for conserving time and energy. Using these techniques and strategies, you will be more organized, able to work smarter, and most important, be more independent than you otherwise would have been.

1. Keep balance in your life. Prioritize, eliminate, consolidate, and streamline activities in all aspects of your life.
2. Plan ahead. Be sensible about how you spend your time and energy. Do those things that are most important to you and to your family. Try to eliminate unnecessary or difficult tasks.
3. Alternate periods of activity with periods of rest. Pace your activities. Try to break an activity down into a series of smaller tasks. Rest before you become exhausted and, if need be, enlist the help of others.
4. Eat a healthy diet. Do not skip meals. Carry trail mix, nuts, and/or fresh fruit with you. Eat a healthy snack, and avoid the temptation to grab a candy bar with hollow calories and little nutritional value.
5. Arrange and organize your home for your convenience. Sometimes, this means putting furniture in strategic locations to help you walk from room to room or placing a chair halfway down a long hallway so that you can stop to rest. Sometimes, it means purchasing duplicate cleaning supplies for both upstairs and downstairs rooms.

6. Accept the fact that you need help from time to time. We all do, whether we have MS or not. Don’t look at it as giving in. Instead, look at it as making an intelligent decision that will make your life easier and safer.

7. Smart-home technology makes it possible to adjust the heat, lights, ceiling fans, sound, and even open or lock doors from the comfort of your bed or easy chair. Remote-controlled devices, cordless phones, and cell phones save steps.

8. Computers are good for keeping records, journals, and writing letters—which can even be done hands-free with voice-activated software. Synchronize your computer with your cell phone and tablet to keep track of appointments and your schedule.

9. Apps for your smartphone or tablet can help you communicate from one part of the house to another, indoors or out; monitor the safety of a loved one in another room or from afar; turn your smartphone into a flashlight; let you keep track of the news and weather (even alert you to approaching bad storms); and listen to the radio or watch TV or movies.

10. Keep abreast of changes in technology by visiting your computer store, big-box store, or phone carrier and ask for assistance on which software or apps might work best for you. Make full use of every option and new app that might be helpful to you.

11. An Internet connection can expand your research capabilities and provide opportunities to communicate with others who have MS.
12. Stay safe by keeping in touch. Walkie-talkies, which don’t require an Internet connection, and smartphones can help you communicate around the house or while shopping, traveling, at museums, theme parks, art shows, or anywhere you might become separated from others in your group. Walkie-talkies are sold at electronic, discount, or office-supply stores. Turn your cell phone into a walkie-talkie by downloading an app from your mobile phone app store.

13. Use labor-saving devices. Many labor-saving devices are available to make almost any task easier. Automatic can and jar openers, toothpaste twisters, hair dryer holders, and quick-release mops are just a few of the many products that may make everyday tasks easier for you to accomplish.

14. Purchase reachers and keep them where you need them to extend your reach or help you pick up or grasp objects. Reachers come in various lengths, weights, and means of operation. Some have trigger grips, similar to a pistol’s, which are operated by squeezing your finger. Others have full-grasp handgrips that allow you to squeeze with all your fingers. Some reachers have magnets at the end for picking up metal objects. Others have rubber grippers or vinyl-covered tips for better holding power. Some reachers fold in half for traveling or storage, and some come with a carrying attachment that clamps the reacher to a walker or wheelchair.

15. Conserve energy whenever and wherever possible. Pushing a grocery cart may give you added stability as you walk. If fatigue is a problem, use a wheelchair or scooter whenever walking distances is required. A growing number of stores, shopping malls, museums, zoos, art galleries, and attractions provide battery-operated scooters or wheelchairs for patrons who tire easily or have trouble walking. Scooters and wheelchairs usually are available on a first-come-first-served basis at the service desk or information booth.

16. Before going out, call ahead to a restaurant, theater, new doctor’s office, and so forth, and ask whether the facility is
handicap-accessible. Ask about parking facilities, where the restrooms are located, the most convenient entrance—anything that might create a challenge or is of concern to you.

17. If noisy environments in restaurants, grocery stores, and department stores exhaust you, select quieter places in which to spend your time. Look for places with drapes, low ceilings, and carpeted or vinyl floors that absorb the sound; avoid establishments that have wooden floors, walls of windows, loud background music, multiple TVs, or high unfinished ceilings. As an added safeguard, carry earplugs in your purse or pocket.
CHAPTER 2

The Thriver’s Guide

In this life, we don’t always understand why things happen the way they do. It’s human nature to ask, “Why did I get multiple sclerosis? What did I do to deserve this? Did I do something wrong?” There are no answers to these questions. So, when I was diagnosed with MS the questions I struggled with were, “How was my life to have meaning? What was the purpose? What was I supposed to learn?”

The biggest challenge of my life has been finding peace with my life as a woman with a severe disability, a wife, mother, grandmother, daughter, sister, friend, neighbor, and coworker.

Philosophically, I believe that there were/are important lessons for me to learn in my life and MS provided the school. To this day, I continue to learn about myself, my strength, and how resilient I am. MS has also taught me lessons in compassion, humility, and gratitude.

The following essays share how I have learned to live and “thrive” despite the challenges I’ve faced. I hope these stories, examples, and real-life experiences provide validation, hope, and encouragement to you and reinforce that you too cannot only survive MS, you can THRIVE!

Accepting the “New You”

Every August, the month of my diagnosis, I “celebrate” the anniversary of my life with MS. “Celebrate” seems like a strange word to use around an illness that at onetime left me with no use of my legs and only limited use of my left hand. Yet, it’s true. I do celebrate my life, limitations and all. So how does one come to this level of acceptance? As you might guess, it was not easy and it did not happen overnight.
Whether it was a small loss like not being able to cut my own food or a large loss like no longer being able to walk, I was in a constant state of grieving. Frustrated by my lack of control, I was petrified of the future. It wasn’t easy to stay positive, and I can tell you I threw many a “pity party” where I was the guest of honor.

Yet, somewhere inside of me a little voice said, “I don’t want to be sad and unhappy. It’s too painful.” It took me a long time to understand that if I wanted to heal the emotional pain of my losses, I was going to have to work on changing the way I dealt with life.

So I began making an effort to participate in activities with family and friends, even if all I could do was sit and watch them bowl, dance, or garden.

I tried to participate in household activities—folding clothes and drying dishes, even if I couldn’t do the laundry or cook the meal.

I traded in my leadership role in organizational work for a “supporting cast” position, making phone calls and setting up meetings. I enjoyed the involvement and people were happy to have my help.

I’ve learned that my self-worth and value are not contingent on my physical condition. Living with MS has taught me that having time for people and relationships is a gift of immense proportion. In my world, that’s cause for celebration!

**Reassessing What’s Important**

I used to think that life was about giving to and doing for others. It wasn’t until I was “in a wheelchair with one hand tied behind my back” (i.e., severely disabled) that I realized that it’s relationships and our ability to connect with those we love and care about that gives our life meaning.

Right before my father passed away, he told me that one of the reasons he fell in love with my mother was because she was such a good listener. Looking back, I now understand that I learned how to be a good listener from my mother.

In fact, my family always teases me because I have an uncanny way of connecting with everyone from good friends to recent acquaintances. Whether it is the air-conditioning repair man, the
person who sold me a pair of shoes, or the checker at the grocery store, people share with me intimate details of their life.

I began to wonder why people opened up to me so easily and I came to this simple conclusion: People are so busy running through life that they don’t have time to stop and truly listen to each other. Because I can’t race through life, I have the time to lend a listening ear.

Perhaps my father had discovered the reason why we have two ears, but only one mouth—we are supposed to listen twice as much as we talk.

Being a good listener is the most important lesson of all and a simple way we can repay, respect, and reward the people who make a difference in our lives.

**Telling Family and Friends How They Can Help**

We’re “lucky”; we have a diagnosis and our illness is one that people have heard of. It validates our complaints and symptoms and adds credibility to our limitations. Our friends and loved ones want to be helpful and lend their support. It’s our responsibility to share with people how they can help us.

Many years ago, a girlfriend told me about her husband who had gone into the kitchen to get himself a drink. She mentioned to her husband that she, too, was thirsty. When her husband returned with his drink, but not one for her, she snapped at him for not bringing her a drink.

So often, we expect people to read our minds, when we really have not been clear about what we want. We have to be specific.

I loved it when my parents came to visit from their home 90 miles away. They were willing to help and did so in many ways: like taking care of the children, helping with meal preparation, and doing household tasks. They were wonderful. But . . .

I’d see the anguish in my father’s eyes as he fought back tears watching me struggle to do things that once were easy. The steady decline in my physical abilities was painfully obvious and I finally
worked up the courage to say the words I needed to say. “Dad, I can’t stand to see you cry whenever you look at me. Cry on your way here and on your way home, but, please, don’t cry in front of me. This is hard enough without seeing how painful this is for you.”

When we express our thoughts and feelings in clear, caring, and loving ways, we strengthen our relationships.

**Staying Connected and Involved**

“I’ll just stay home,” was my immediate response when activities were planned. “Really, just go without me. I’ll be fine by myself,” I reassured my family and friends. But the truth was I was not happy that my world was getting smaller. And I was the person responsible for making it that way.

When I found my world shrinking, I pushed myself to invite good friends over for lunch even though they had to help prepare, serve, and clean it up. At first, I was embarrassed asking my friends to make their lunch and mine, but I learned that they loved being able to help and were happy that I wanted to continue our friendship. Being with good friends was a brief respite from my worries.

More than 30 years ago, I invited a group of women over to play cards. The game was, and still is, always at my house because then I don’t have to stress about accessibility issues, the weather, and if I need to lie down, I can, while the game continues. Over the years, we’ve shared lots of memories and belly laughs. Members of the group take turns bringing refreshments. And the women understand that if I’m having a bad MS day and not up to having the game, someone else hosts the game at their house.

Several years ago, a young immigrant from Armenia came to visit me to practice her English. Now an American citizen, she recently told me, “I can never repay your kindness. As long as I am alive, you will never be alone.” Her words touched my heart and brought tears to my eyes. And all I did was invite her to my house to talk!

When I don’t feel up to being social with my friends and neighbors, I can connect on my own time by “talking” with folks on the Internet. In addition to using the Internet to connect with others
who have chronic illness, I’ve used the Internet to locate former classmates, people I used to work with, and long-lost relatives. Day or night, I can stay connected to the world beyond me.

It’s not fair that we have a chronic illness. However, we owe it to ourselves to reach in and reach out. Our lives will be more fulfilling, more interesting, and we won’t get stuck feeling sorry for ourselves and “our lot in life.”

Making Compromises

Life is full of compromises. But I wasn’t interested. I was angry, stubborn, and I was not going to give in to MS! I was not going to use a #!%#&!# wheelchair! I wasn’t going to be one of “those people.” Does that sound familiar? Whether it’s wearing hearing aids, using oxygen (at home or in public), or an ankle/foot orthotic (AFO) with “dorky-looking” shoes to help (me) with foot drop, it’s not easy to accept our limitations no matter how old we are.

I remember when my father-in-law, who was in his 70s and had Parkinson’s disease, refused to use a wheelchair when we went to the National Aquarium in Baltimore, Maryland. We were visiting from Wisconsin and wanted to take our 14- and 12-year-old children to see the sites. We knew that if Grandpa wanted to join us, he’d have to use a wheelchair. If he didn’t, he would have ended up sitting on a bench in the lobby waiting for us.

At the time, I was 42 and had been using a three-wheeled, battery-operated Amigo® scooter wheelchair (www.myamigo.com) for several years. I remembered how hard it was for me to accept using a wheelchair. In fact, years earlier, we had gone with my in-laws and the children to an amusement park. By the time we walked from the parking lot to the park entrance, I was exhausted. I found a bench and never left it the entire day. The family, at my urging, went on without me. I REFUSED TO USE A WHEELCHAIR! Even though it meant missing out on all the family fun.

I reminded my father-in-law of that day and asked whether he remembered how he felt leaving me on that park bench while he and the children went off to see the sites. He did. And so he (reluctantly) agreed to use the wheelchair. Halfway through the aquarium,
my father-in-law gave me a wink and a smile and said, “I could get used to this.”

Making compromises is not easy. However, if we don’t, we put limits on our lives and miss out on wonderful opportunities and priceless memories.

**Asking for Help**

Before I started using a wheelchair, I was out with some close friends. To get to our destination, I had to go down some terrace steps. I was unsteady on my feet normally and was terrified that I would fall down the steps (in front of everyone) because there was no railing for me to hang onto. I stood at the top of the stairs paralyzed with fear. Engrossed in conversation, my friends kept walking, until one turned to look to see where I was. In that split second, I made the decision to ask my friend if I could take her arm so I would have the extra support I needed. I made it down safely and looked around. No one was staring at me. No one cared that I needed help. People were “in their own little world.” Wow! Was that an “ah ha! moment” for me and a paradigm shift in my thinking.

I’ve asked for lots of help over the years and have never been turned down, even in the most embarrassing circumstances, like the time I was downtown at one of the state office buildings for a meeting. My friend had dropped me off so I was on my own. As I entered the building, I felt the need to use the ladies room. I started getting panicky because I wasn’t with anybody who could help me. As I walked past different offices, I realized that if I didn’t want to find myself in a horribly compromised situation, I’d better ask someone to help me.

And that’s what I did. I approached a woman behind the desk in one of the offices and told her I needed help and asked whether she would mind helping. At first, she only thought I was looking for a ladies restroom. I explained how I needed a little more help than that. She looked me in the eyes and said, “Of course! What can I do to help you?”

When I was back in my wheelchair, waiting for the elevator to take me up to my meeting, these words echoed in my mind: When you ask for help, someone will always be there to help you.
No, it hasn’t been easy! I hate the fact that I need so much help; but when I stop to think about it, asking for help has given me a lot more freedom and, perhaps, people are learning some compassion for others, something our world desperately needs.

Letting Go

Someone once asked me what was the most important lesson I have learned on my MS journey. I knew the answer immediately: learning to LET GO. Examples of that surface every day and are constant reminders of its importance.

In the early years of my diagnosis, my hands were becoming weak and stiff, which meant that someone had to spread cream cheese, peanut butter, mustard, and so on, on my bread or crackers. At the time, it seemed like a small, petty problem; but it bothered me because we all have personal preferences, especially when it comes to food. And, even though I asked the person helping me to put on “a thin layer of peanut butter,” it didn’t turn out that way.

For me, it was the reality of “another loss.” Losing abilities and becoming disabled was emotionally painful. Learning to “let go” eased the pain.

I haven’t driven a car since 1985, so when relatives, friends, and neighbors drive me in my ramp-equipped van, they choose the route (through town or on the highway), the amount of time we need to get to our destinations given weather or road conditions, and where we should park. I give them the control. I’ve learned that some drivers know exactly where we’re going and don’t need any directions, whereas others want me to tell them every turn and lane change, no matter how many times we have gone to the same place. Some worry and need constant reassurance. Some go a little faster than I would if I were driving, whereas others barely keep up. Accepting that others do things differently and letting go has reduced my impatience and frustration.

I’ve also learned to let go of perfection. So what if some of my drawers are not picture-perfect? I’ve given myself permission to just toss my underwear, socks, and nightgowns into the drawer. My rationale: Who cares? And it saves time and energy for more important things.
Putting Yourself First

I was a doer. I was always taking care of other people. I rarely thought about my needs or my wants. Who had time? I was too busy.

And then MS put an end to my life as a doer. I had to learn an important new lesson for living, and it was not easy. What was this lesson? You MUST take care of yourself by putting your needs first.

I am not suggesting that you be mean, thoughtless, demanding, or selfish. I only encourage you to love yourself enough to “take care of you” and do things that bring love and joy into your life. Most important: Give yourself permission to get rid of “toxic” people in your life. If you cannot eliminate them entirely, reduce your exposure or “dilute their toxicity” by including others when you must be together. People who are negative or pessimistic drain your energy and pull you down.

Having my nails done is one way I take care of myself. I have always wanted nice-looking nails. When my hands lost their strength, my nails started to grow out. Today, my pretty (red) nails put a big smile on my face. Over the years, my girlfriends and I have gone to the local beauty college to get manicures. The cost is nominal and I have met dozens of terrific young men and women.

Putting yourself in positive, uplifting situations and surrounding yourself with good people will help you let go of your anger, frustration, and disappointment over “what might have been.” When you make room for smiles and laughter, people want to be around you and include you in their lives.

Talking to Yourself

I start my day with a personal pep talk. Each morning when I look in the bathroom mirror at my bedraggled mop of (naturally) curly hair and baggy/saggy eyes, I could say, “You are one scary lady!” But before I allow my mind to go there, I say in an upbeat voice, “Good morning, Sunshine! Happy (Satur)day! I’m a valuable, worthwhile person and I’m ready to face the world and the challenges that come my way.”

Going through my morning routine, I focus on sending positive messages to myself: “That pink turtleneck I’m wearing looks good on me.” “The fog and humidity in the air today will make my curls even curlier.” “I like these new glasses; they frame my face nicely.”
As I put the finishing touches on my hair and makeup, I look at my reflection in the mirror and utter these exact words. “You look great! Shelley, I love you. Now, go and make it a wonderful day!”

My children would be horrified to hear that I talk to myself like that; they’d think I’ve gone over the edge with my own self-importance. But I’d beg to differ.

I will admit that when I started these morning rituals, I felt foolish, even embarrassed by how ridiculous it sounded. But on the days that I forget, I actually feel less positive and energetic.

Other things I say to myself . . .

When life threatens to overwhelm me, I repeat a mantra. Sometimes that mantra is, “Keep breathing. Keep breathing.” Sometimes it’s, “Just do one thing.” And sometimes it’s, “You’re gonna be fine.”

I also refuse to “should” on myself. Phrases like I should write, I should call, I should send, I should go, I should make, and so on are no longer in my vocabulary. When you remove the negative “should,” you can change the phrase to a more neutral or positive statement.

I pay attention to what my body tells me. If, for example, I’m tired because I didn’t sleep well, I’ll take a nap. I do not allow myself any negative or judgmental self-talk. I kindly give myself permission to “take care of me.” After all, if I don’t “take care of me,” who will? Slowing down means I get more done. I make fewer mistakes, use less energy, and reduce my stress and tension overall.

We send ourselves messages all the time. Doesn’t it make sense to give ourselves loving and healing messages all day long?

**Taking Responsibility for Your Happiness**

Can you ever be happy again after you’ve been diagnosed with an incurable, progressive illness like MS? I’d like to think you can. For me, the answer was accepting that I deserved to be happy and understanding that it was up to ME to make it happen.

A parenting story I had written filled five pages in the National Multiple Sclerosis Society magazine, *Inside MS* (now *Momentum*). Our family picture graced the cover! I was thrilled! But my family’s reaction was less than enthusiastic.
My husband, Dave, remarked, “You said our picture might be on the cover. You didn’t say we’d be the cover!” Our 16-year-old daughter was “totally embarrassed” and our 14-year-old son glanced at the picture and asked, “Are my soccer shorts still in the dryer?”

After 3 days, the magazine was still in the same place on the table. No one had read the story, making me feel great disappointment and frustration with them.

I wondered how my family could give such little attention to what was, in my eyes, a gargantuan accomplishment. I had given up so much since MS entered my life. What were the chances of someone with my level of disability and no professional writing experience having a cover story in a national magazine? For some reason, though, my family did not seem to recognize what a great moment this was for me.

With each passing day, my depression grew. One afternoon, after crying until my eyes nearly puffed shut, it hit me! I was not going to let this disappointment pull me down any longer. I was going to take responsibility for my own happiness.

I called a local florist and ordered a basket of flowers to be delivered to my home. When the clerk asked whether I wanted to enclose a card, I said yes and dictated the following: “Congratulations! You’re terrific! I’m proud of you. Love, Shelley.”

Yes, that afternoon, my family and I learned an important lesson about happiness. You have to be good to yourself and celebrate your accomplishments, big and small.

I work hard to bring joy, happiness, peace, and enjoyment into my life (and sometimes this is very difficult). For example, at times, I just have to take a break from watching or listening to the news. So often the news is filled with pain and suffering that it only reinforces my feelings of helplessness and hopelessness.

Something I learned years ago from a therapist was “whatever has brought enjoyment to you in the past, try to connect with it again.” I know that when I’m writing about my family, childhood memories, and experiences living with MS, I get lost in what I’m writing. It’s like a vacation from my reality. I can also “disappear” when I’m on the Internet making photo books for the family or trying to learn Spanish.
Building a Support System

When people told me that I should attend support group meetings, I REFUSED to go. In fact, I didn’t attend my first support group meeting until I had had MS for 10 years. Even though I was in a wheelchair, I did not identify with “those people.” (Talk about denial!) No matter how old you are or what stage your MS is in, accepting your limitations, increasing disability, and an unknown future is difficult.

We can’t do it alone, nor can we depend only on our family, friends, care partners, or others for all the support we need. In many cases, they are hurting as much as we are over our situation. In addition, they can’t know what we’re going through like others who are living with MS. Talking about how relationships with our family and friends have changed, the stress of raising kids, the inability to continue working, and the need to consider using a mobility device are only a few of the difficult issues we often need to confront.

Creating your own support system may include joining a support group, which is usually facilitated by a lay or professional leader. Meetings can include speakers; focus on a specific topic, like depression or fatigue; be social get-togethers; or a combination of all of these. Contact the MS organizations in Chapter 15 to find out whether there are support groups where you live.

Another place to find support is to contact hospitals and clinics. They often offer coping-type support groups for people with chronic illness or those who are going through life-altering changes. This kind of group will not be MS specific, but it will provide important coping strategies for living with chronic illnesses like MS.

If attending a support group is not your style or you’re afraid to see others with more advanced cases, you may want to start your own small “support group” through your faith community or meet for lunch or coffee with a few selected people who are “kindred spirits” and are dealing with similar issues. Or consider connecting with people who are taking a drug you’re taking (or considering taking). Patient educators, drug company representatives, and patient ambassadors can answer questions and provide important information and support.
If the everyday reminders of the difficulties you’re having are too much for you, talk to your doctor. Talk therapy and medications can help with sadness, depression, and getting through difficult times. Taking an antidepressant and talking with a counselor or therapist has helped my husband and me deal with all the changes we’ve faced over the years. Sharing our struggles with a mental health professional improved our communication and taught us how to express our feelings in caring and loving ways. And even after living with MS for nearly 40 years, we still need a “tune up” every now and then—that is, a medication review and consultation with a therapist. Sometimes I see the therapist on my own when I “just need to talk.”

Setting up a support system is up to you. In the same way, your care partner has to set up a system that works for him or her. Without proper support, living with MS is difficult at best. Take charge and create a system that works for you.

**Journaling**

Ever since my diagnosis in 1979, I have used a journal to record my thoughts, fears, feelings, and frustrations. I don’t write every day, but I write about everything and anything—from problems I’m struggling with to interactions with doctors, from ideas for remodeling the kitchen to how I would manage when I could no longer walk or use the bathroom independently.

Writing in my journal gives me a safe place to vent, laugh, cry, worry, and share what is in my heart. After each writing session, I feel the calmness that you feel after a “good cry.”

What I didn’t realize when I started writing my stories and feelings was it was a way to leave a piece of myself behind. I knew that my illness was not a terminal disease. However, as you know, losing abilities can make you feel as if you are dying.

I wasn’t sure how long I would live. Would I see my children go to high school? Enter college? Get married? What words of praise, encouragement, and congratulations would be missing from their lives because I was not there to utter them? What profound questions like “how will I know I’m in love?” would go unanswered? And the biggest question of all, what, if anything, would they know or remember about me?
I still write in a “journal,” but now it’s on the computer. And, to be honest, I’ve never gone back and read those first 25 years worth of entries. I know it would be too painful and sad to read how I felt back then. I know what’s in them and I don’t ever want to go back there. The notebooks are evidence of where I’ve been, how I’ve been tested, and how I processed my MS diagnosis. Just being there, in the file cabinet, gives me the courage to look forward because I now realize that I’m a whole lot stronger than I thought I was.

Consider writing “your story” and see what you learn about yourself.

Laughing Again

“Laughter is like changing a baby’s diaper. It doesn’t permanently solve any problems, but it makes things more acceptable for a while.” I don’t know who said that, but to me those words are a perfect analogy for life with an MS.

It is hard to laugh when you’re grieving your losses, worried about the future, and frustrated by your lack of control. But I believe it is absolutely essential that we laugh because it makes the journey easier.

Even when I’m in the pits of my depression, I try to find some humor in the situation. One time I told Dave, “Well, when my eyes are swollen and puffy from crying, at least my wrinkles disappear!” I borrow DVDs and watch videos from the library or from friends and have found that I Love Lucy reruns and funny movies (Animal House and Weekend at Bernie’s are my favorites) give me belly laughs.

Funny situations and circumstances are all around us. Here are a few of my favorites:

• I was explaining to my son’s friend that I used to be right handed but now I’m left handed because of MS. Excitedly he said, “I know; that means, you’re amphibious!”

• Then there was the time that my girlfriend, her 11-year-old daughter, and I went to the mall. My friend pulled my lift-equipped van into a handicapped-parking stall, which prompted her daughter to say, “Mom, we can’t park here.” From my wheelchair in the back of the van I said, “Nancy, it’s OK. It’s for me.” We all had a good laugh and I learned that people, especially
children, don’t necessarily see your limitations, even when they’re obvious.

- When our son, Andrew, was in 5th grade, his art class assignment was to make a sign. Always full of “surprises,” he asked the art teacher how to spell the word *crippling*. The teacher was a little reluctant and asked Andrew why he wanted to know. He replied, “I’m making a bumper sticker for my mom’s Amigo” (my three-wheeled battery-operated scooter). I can only imagine the teacher’s reaction, perhaps concerned that the word might hurt my feelings. Andrew reassured her, “It will make her laugh!”

- The day he brought the “bumper sticker” home he couldn’t contain his excitement. Yanking it out of his backpack, he held up the 24” cardboard sign. In big bubble letters it read, “KISS THE CRIPPLE.” I laughed so hard I cried; my reaction didn’t disappoint Andrew. For months, we kept the sign on the front of the refrigerator and the laughter it sparked was priceless!

Self-deprecating humor or laughing at oneself is another way of finding a way of bringing laughter into your life. When I speak to audiences about strategies for living with a chronic illness, I share my personal story and add that “a strange thing happened when I lost the use of my legs and dominant right arm and hand; my mouth got bigger.”

One last thought: It’s impossible to cry with a smile on your face!

**Getting Out**

I was a master at making excuses for not going out—it’s too hot, too cold, too far away, too much walking, too noisy, and so on. My favorite was “no one will miss me.” It was just easier to stay home. People don’t realize what an effort it takes for someone with a chronic illness to go out.

When I gave up driving, the kids were still in elementary school. Dave was wonderful and provided many rides. But by now, he was doing “my jobs” as well as his own and I hated asking him to take time off work or add one more thing to his to-do list.

I found that finding rides to school and school activities was easy. Other parents were taking their kids and kindly agreed to take

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mine, too. I always shared in the cost by contributing money for gas. By doing so I didn’t feel as guilty asking for a ride or being part of a carpool, and people appreciated my monetary “thank you.”

I don’t remember exactly when I started giving myself permission to call and ask people to drive me places. But what a difference that decision has made!

Yes! It gets old having to find a driver every time I have a doctor’s appointment, need a haircut, or to go to physical therapy. Many times I’ll have to make five or six calls before I find someone who is free to drive me.

If I wanted to attend a meeting, event, or get-together, I didn’t wait for friends to call and ask me whether I needed a ride. I called them. First, I asked people who I knew were already going whether they would be willing to drive me in my ramp-equipped van. Recently, I joined a women’s group so I called the president and asked whether she knew someone coming to the meeting from my neighborhood who might be willing to drive me. She did.

My “drivers” know that if they aren’t available, they have to be honest and tell me. No guilt, no embarrassment, no judgment! Many folks who aren’t available will often suggest others who might be able to drive me and/or they’ll say “please call me again any time.”

Thankfully, people are still willing to drive my ramp-equipped van to where I need to go. However, I’m careful not to ask the same people over and over again so I don’t “wear out my welcome.”

After all these years, I still don’t like calling and asking for rides, but I refuse to give up my life because I can’t drive. There are lots of good people out there to get you where you need to go. I know, because over the years, I’ve gotten hundreds and hundreds of rides, met lots of interesting people, and along the way, made some new friends.

For vehicle adaptations and modification to make it easier to drive, see Chapter 13.

Helping to Find a Cure

On days when I’m feeling low or guilty for all of the things I can’t/don’t do, I try to connect with a cause greater than my own, like raising
funds to support MS research. Many people don’t know what MS is and they’ve never known anyone who has it. So, whenever I have an appropriate opportunity, I tell people that I have multiple sclerosis. I’m open to their questions and am grateful for their interest.

People tend to donate more to causes when they know someone who is affected by the illness. So, when people ask you how they can help, tell them to make a donation to one of the MS organizations listed in Chapter 15 because they all fund research and provide programs and services to people with MS.