

So You Have Progressive MS?

MANAGING MAJOR CHANGES



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National
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Rick (front cover), diagnosed in 1991.

So You Have Progressive MS?

BY SHARON M. BROWN

For Aliyah, my love and my life, with many thanks to Dad and Ann for all their help, and in loving memory of Hannah, Joan, Einar, and Carol, all of whom encouraged me to follow my dreams. –SMB

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Introduction

If you're anything like me, this pamphlet may be one of a dozen books, magazines, and articles you've gathered now that your doctor has told you that you might have, or probably have, or even definitely have progressive multiple sclerosis. Progressive is not a word any of us want to hear.

I hope you're not bogged down in a lot of technical material. Maybe some words from a veteran like me will help.

There are lots of ways to view this disease. I sometimes think of my MS as a bizarre train ride that speeds up or slows down, throws me off my feet, or proceeds gently and uneventfully. But I never know. When I look back at my 11-year journey, I often think of it as living in a carnival, with me occasionally on the Tilt-a-Whirl, leaving me staggering as I get off; or in the House of Mirrors where everything looks really peculiar.

However I describe it, life is never boring with multiple sclerosis, so even when I feel I've lost all my other senses, I hang on hard to my sense of humor.

Let me skip to the "end of the story" first. The majority of people with MS live a nice, normal, life span, even with progressive disease. Most of us don't have to expect that a wheelchair or bed will become our long-term home tomorrow. In my case, the disease has progressed fairly rapidly. About 15 percent of people with MS are progressive

from the start, as I was. Many more people start out with the relapsing-remitting pattern of MS, but after a time — well, you know your own story.

Within two years of my diagnosis, I was in a scooter almost full-time, although I could and **can** still walk. The scooter didn't stop me from working or playing with my daughter (who was two when I was diagnosed), or helping to care for my mother, who also helped care for me. I have also dated, worked, and socialized.

The past 11 years have had highs, lows, tears, laughter, change, and, well, life. I doubt that anyone describing any 11-year period would say anything different, MS or not.

For me, MS has not been a smooth, sight-seeing kind of train ride, but it hasn't been an endlessly dark tunnel, either. What it will be for you may be completely different from what it has been or will be for me. Nonetheless, there are probably some things about MS (which I often say really stands for "massively strange") that we share.

Diagnosis

Before I was diagnosed, I remember feeling like I was trying to put together a million-piece, tissue-paper jigsaw puzzle while sitting outdoors in the middle of a tornado. There were all sorts of weird symptoms that didn't make sense. Numbness and tingling; stiffness and pain; and sometimes I couldn't get my body to do what my brain told it to do.

One of the best days of my ride with MS was the day I finally had a name to put to my strange symptoms. It was a relief to know that what I was going through wasn't all in my head. (Even though it is in my head — MS is in the brain and spinal cord, also called the central nervous system.)

For those of you who got a diagnosis of progressive MS after years with relapsing-remitting disease, the doctor's news was a tough thing, not a relief. You hoped it would never happen. But now that you're here, I hope you can join me in looking forward.

Coming soon . . .

By far, the best thing about MS right now is the future. When I began my journey, there were a few drugs to treat some symptoms. Now there are more and better ways to manage symptoms and some approaches to slowing this thing down for some forms of progressive MS. I am hopeful that there will be better treatments for all of us. There may even be stations where we'll get off, if not forever, at least for a nice long while.

The journey

Some of you used to have remissions, when almost everything went away. I've never been in remission and don't know what it's like. While I do not experience remissions, all of us, with MS or not, live with limitations.

Some limitations — like buildings that are inaccessible — are barriers that society creates; other limitations are barriers we place in front of ourselves — like deciding that we can't do something anymore because we have this disease.

If you can, try viewing your limitations as hurdles to go over rather than walls to stop you. Sometimes, after not making it over a hurdle a few times, I've had to admit that I just can't. Then I have to try to work around it some way. I don't stop trying. When it comes to a disease like MS, attitude is everything!

If I call myself a “disabled person,” rather than a “person with a disability,” then I let the disease win by defining me. Yes, I have MS. I also have brown hair, and a daughter. In and of themselves, none of these things are me. I am not just disabled any more than I am just a mom or just a brunette. Neither are you.

Becoming a health care manager

Back when I was a full-time health writer I was often asked if I liked the idea of managed healthcare. My answer, then, as now, is “Sure, as long as I'm the one managing my health care.”

I believe no one knows your body or your life the way you do and no one can be your medical advocate but you. Having MS doesn't take that responsibility away. Being in charge of your health care means keeping up with your entire health: physical, mental, emotional, social, financial, and spiritual.

I always try to be on top of my upkeep and handling, but that doesn't mean I do everything alone! Far from it. It does mean I've learned to take responsibility for informing people about what I want, and, just in case, about what help I might need.

Managing mental health

Having support is vital. It took me a while to get it, but I finally realized that as long as I expected to “pull myself up by my bootstraps,” I might spend the rest of my life staring at the ground. We all need people with whom we can vent freely and explore options and solutions. We need people who won't take it personally and try to fix everything, as people who love us might like to do.

Finding that support sometimes takes a bit of work. Your family and friends may be your first line of support, but I've found that it's sometimes just as difficult for them to hear about my MS as it is for me to talk to them about it.

Sometimes MS feels like you're walking a high wire blindfolded. Adding new people makes your safety net wider and stronger. I've gotten a lot from an online support group. Face-to-face groups are good too. Volunteering at the National MS Society will put you in contact with others who have MS, and making some friends who share this disease really expands your options.

I've found I need more than good friends. I've had a counselor of one type or another even before I was diagnosed — back when I thought my bizarre symptoms meant I was going crazy. I've had counselors who didn't know the first thing about MS to start out with, so I taught them! The best part about having a counselor is that I can complain and cry without feeling guilty. Unlike friends, I don't have to worry about burdening my counselor. Unlike family members, I don't have to worry that a counselor won't be able to handle it. It's a professional relationship.

No doubt you've heard of the various stages of grief: denial, anger, bargaining, depression, and acceptance. Well, those are stages of living with MS, too. But, don't expect to get through one stage and on to the next, as if they come in some set order. They don't.

I go through the stages all the time. Whether it's the first time for a new symptom or whether I'm feeling the same thing for the umpteenth time. At some point, I know now that I'm going to get angry, feel depressed, deny anything is happening at all, and, eventually, come to terms with it and adapt to it. It's a continuous cycle.

Because this is a disease of constant change, don't feel guilty if you can't just “learn to cope” with all the things that may be going wrong at once. You have every right to have some problems coping with all this! I hope you'll learn to

give yourself a break. If you need help finding help, that's okay too. Try calling an MS Navigator® at the National MS Society. The staff can't change your life, but they sure are easier to hang on to than those bootstraps.

I've always found it ironic that depression is not only a result of having this disease, but also the result of MS lesions in certain parts of the brain. In other words, depression can be a symptom of MS just like any other. No matter how you look at it, don't be surprised if you have to battle some form of depression.

Clinical depression isn't just "the blues." It's a low that lasts for weeks and it's a serious health problem. Some of the symptoms include ongoing problems with self-esteem and loss of interest in everything. I've been there, just staring at the ground, not caring about anything. When I got the right medication, along with counseling, I found I could look up again and see joy in the world around me.

No one is at fault for becoming depressed, I've learned. As crazy as this disease can be, we'd really be around the bend if MS never triggered a serious low. Research shows that more than 50 percent of people with MS will suffer from a clinical depression at some point. So treat depression just as you treat the rest of MS: Find the right health care provider; get treatment; get on with your life.

One other thought: Taking care of your spiritual health is an important part of the whole you. Don't overlook what you can receive from whatever spiritual beliefs you have. This may or may not mean going to regular services. It does mean that the MS train takes you on a trip that poses some heavy questions about how you see the world and your place in it. Spiritual advisers might offer important support for this part of living with MS.

One emotional aspect of MS surprised me very much. I've found myself crying uncontrollably at TV commercials and then being unable to cry at appropriate times, like funerals. A few years ago, I told my neurologist about my weird crying spells. He said the medical name for this is "pseudobulbar affect" (PBA) and explained that people can experience uncontrollable laughing episodes as well. What makes these episodes so uncomfortable — and so confusing — is that the crying or laughing are unrelated to how a person is feeling inside. Medication can relieve this symptom, so speak to your neurologist if this is bothering you.

Managing physical health

I wish I had learned early on to write a journal, keeping track of my health as it changed. I remember thinking I would never forget what went wrong first or when, but after 11 years I don't remember.

So, here's a suggestion: Keep a journal in a bedside drawer and whenever something changes, start a new page with the date at the top. Draw a stick figure and use circles or arrows to indicate changes in spasticity, weakness, numbness, tingling, pain, whatever. Then, as the symptoms change, redraw the stick figure and change the areas you've marked.

Assuming none of the symptoms are bad enough to make you call your doctor immediately, you can take your journal with you the next time you go to the doctor and discuss it. Write down questions, too, as you think of them. If your doctor doesn't like answering questions, or if you or a companion who goes with you to appointments aren't given time to write down the answers you get, then don't think twice about thinking twice about your doctor.

Remember, you employ your doctor. Even with a very stringent HMO, you should have some latitude about whom you see for medical services. That doesn't mean you shouldn't give your doctor a chance. Every doctor is different. But it's important to find a doctor who makes you feel comfortable, respects you, and doesn't intimidate you.

I like to imagine health care as an old-fashioned railroad handcar. One person has to push the handlebar down. When it comes up on the other side, the other person has to push it down. As you work together, you build up a rhythm and together you're soon eating up the miles. In the best of

all possible worlds, you and your doctor would work like that to keep you as healthy as possible. It's worth a search, maybe even a fight with your insurance company, to find a doctor-partner. You also have to learn to do your share of the pushing — like preparing for appointments by writing things down, and by being as clear and honest as you can.

To be as healthy as you can, you'll encounter many medical "alternatives." I tend to be very skeptical about anything that isn't traditional. It's always smart to be a skeptical consumer, even if you're not like me. Just because someone swears they found relief by eating this or doing that doesn't mean you will get the same results. It's possible to waste thousands of dollars this way. Ask the National MS Society for tips on how to be an informed, careful consumer.

There is one form of "alternative medicine" that I use all the time: massage therapy. My massage is a place where I get to take care of me. I escape from the world and completely relax. So, while the therapist's "magic hands" may or may not be doing anything for my physical health, I know that feeling good helps my emotional health.

Having a healthy lifestyle

Listening to your body is an important part of managing this disease. Some people have to learn this. Others, like me, listen almost too well. Maybe it seems obvious, but

it took me a long time to learn that MS wasn't always to blame when something went wrong. Just because I have MS doesn't mean I need my neurologist when I have a sore throat.

Even with MS, it's possible to have "normal" things go wrong, or have other bad things happen, like cancer or diabetes. The best defense is a good offense. This means having a family doctor, and for women, a gynecologist. This means getting that annual flu shot, if it's right for you, and all the usual preventive tests, be they pap smears, mammograms, or prostate exams.

Try to stay healthy. Do the common sense stuff. Take your vitamins, eat a balanced diet with lots of fruits and vegetables, and get as much exercise as you can. Once upon a time doctors told folks who had MS not to exercise. Now we know better. In moderation, exercise is good for you.

I had to give up hiking after my MS reached a certain point, but that doesn't mean I gave up the outdoors. I modified how I enjoyed it. Maybe you can't go downhill skiing the way you used to, but you can come up with another activity you enjoy. Get out and do that. Trust yourself and your instincts. You can bowl from a scooter, for example, sometimes better than the people who are standing. (Just don't tell them that you actually have an advantage.) Ask your doctor for a referral to a physical therapist (PT) who is knowledgeable about MS and find out what you can do. The PT will work with you to

identify activities that meet your needs, provide enjoyment, and keep you as active and fit as possible. The National MS Society can assist you in finding a PT with experience in MS.

Heat or humidity affects many people with MS. If heat slows you down, avoid it as much as you can. If you can't, be prepared. I think my freezer has at least as many freezer packs to cool me down as it does frozen vegetables, and in a pinch I've been known to use the frozen vegetables as ice packs.

Having a healthy personal life

Everyone's entitled to a personal life. If going out and hitting the nightclubs is something you used to enjoy, chances are good that those two words, "multiple sclerosis," haven't taken away your fondness for it.

I was a single mom when I was diagnosed and I'm still a single mom, but that's been my choice. I have many friends with MS who have gotten married well after their diagnosis. Someone worth making a lifetime commitment to should be able to make a commitment to you regardless of MS.

Okay, it's hard to get the energy to go out and have fun, particularly if you've recently gone through a run of I.V. steroids and gained an extra 20 pounds. But, remember how much you enjoyed getting all spiffed up to hit the town? That feeling hasn't gone away. The reflection in the mirror of you decked out in your peacock feathers is just as fine now. "Weight on the bones" doesn't have to mean "waiting at home."

What if you plan a big night out and the night arrives but the energy doesn't? Welcome to the MS circus — only now you feel like you're in the dunking booth.

You can tell your date that tonight's not a good night to go out, and maybe suggest a video and popcorn at home. If your date can't accept that, then you've just learned a very valuable lesson about that person.

But suppose you haven't told your date you have MS? Just when do you do that? Every situation is different, but I've used this trick. I look at the person and ask myself, "If he told me he had MS how would I feel?" If I barely know the person then I usually think it is too soon to know. If it wouldn't matter to me, then I trust that it won't matter to him either, and it's time to tell. I've usually been right.

You don't need to wear a sign around your neck advertising your MS, even if you use a mobility aid that everyone sees. I have tried to be as honest about my health as I am about my single parent status, for example.

What should you do if your sexuality is affected by MS? Men and women can have both sexual feelings and abilities changed by this disease. If that's one of the dimensions of MS for you, and you have a caring partner, the two of you can explore ways to work around the problems. I have a friend who discovered that there's an entire world of ways to make love without ever "just having sex." Trust me, the twinkle in his wife's eye makes it clear to the world that they have a wonderful relationship in every way.

In other words, there are ways to work around sexual problems in a romantic relationship. The main thing is creating relationships based on trust and mutual respect.

But here's a sad truth. Friendships have given me more than one visit to the dunking booth. I have had to make the hard decision not to continue some friendships that I thought would last forever.

I moved for my job to a city within a two-hour drive of an old college buddy. No matter how many different words I used, I just couldn't explain to her that even though I "looked so good," and was able to work forty-plus hours a week, I couldn't drop everything and join her for a day of shopping. Even harder, I had to accept the fact that I no longer had the emotional energy to support her and listen to all her problems the way I had in the past. Looking back, I wonder how I had the emotional energy to do it before my diagnosis.

A final thought about personal life — don't forget to go on vacation. Just because your body is "high maintenance" doesn't mean you don't deserve time away. There's a whole travel industry booming for folks who use mobility aids, if that's an issue. Just remember to slow down. Don't try to do ten cities in five days. It may take extra planning, or a more conscientious travel agent, but vacations can be as much fun as ever. Your mind will thank you.

MS on the home front

MS is a family disease, and as the old saying goes, you can pick your friends, but you can't pick your family. Hopefully, your parents, spouse, significant other, and children will be as supportive as you want them to be. In reality, though, they make a few trips to the dunking booth too. Give them time, and don't feel guilty about taking care of yourself first. This is another arena where a counselor can help. Your family members can unload on a professional and say things that might otherwise be difficult.

I live in the “sandwich” generation, with a child and with my dad still alive and well. They both spend many an hour worrying about me, just as I worry about them. Making my health a family affair has worked for me. Don't be afraid to ask for help. And don't be afraid to turn help down. As your abilities fluctuate you need to be able to tell the people you are closest to. Keep those lines of communication open. If you don't shut your family members out, if you let them in on what's happening, I'm willing to bet they will come together as a team the way mine has.

How do you deal with your children when you have progressive MS? Telling kids that mom or dad has a chronic illness isn't easy in the first place. And that's just the first step. Your MS will come up in family life, often when you least expect it to. Remember to offer kids the same emotional support system that you've created for yourself. That can include counseling.

They are likely to go through some of the same anger, denial, and depression that you've gone through; and if they're going through puberty too, it's a double whammy! On the other hand, research shows that kids who grow up in families like ours develop compassion, independence, and know-how. Those are good things.

This is another place where the National MS Society comes in handy. They have special programs for children of all ages. These events have been a great way for my daughter to know she's not alone in having a mom with MS.

I have spent many an hour telling my daughter that I am not angry at her; I'm angry at the MS and she just got in the way. But that's going to happen between us anyway whether it's the MS, or some situation at work, or with friends. It also happens in the other direction. My daughter will lose her temper with me when she's really angry about something at school, or some boy, or the MS, or something else. The key, again, is communication — figuring out what's really going on and discussing that.

My daughter has been doing things for years most kids her age don't. She cooks, helps with shopping, and does housework. I've found it helps to admit my limitations to her and to live within them. Trying to do more than I can will just wear me out that much more quickly, taking away quality time from us both.

Taking care of business

I had no place to go but up in my career as a newspaper reporter when I was diagnosed. I was 26. There was no way I was going to let MS slow me down. And it didn't, at least not for a long time. Many people with MS work just as long as anyone else. Like the disease, how long you will keep working is unique to you. There are lots of resources available to help you stay on the job. The first resource for me was my employer.

Most employers would rather keep a happy, productive worker they know than hire an unknown, untrained replacement. Besides, thanks to the Americans with Disabilities Act, getting fired for having a chronic disease or being disabled is illegal. Employers are expected to make reasonable accommodations for your disability, but only after you decide you need the accommodation. Employers aren't mind readers. Unless you tell them what you need, they can't be expected to accommodate you. Accommodations have to be reasonable, too.

Months before diagnosis but after my first symptoms appeared, I kept my bosses informed about what was going on. I decided that full disclosure was the best way for me. In hindsight I wouldn't change a thing. When the time came for me to admit I couldn't work as a reporter any more, my bosses were more willing to help me since they had been in on my struggles from the beginning. Not everyone is as fortunate as I was. Disclosure might not be the right move

for you. For some help with your disclosure decision, you can check out the National MS Society's Disclosure Tool at [nationalMSSociety.org/DisclosureTool](https://www.nationalMSSociety.org/DisclosureTool).

The second most important resource for me was the Department of Vocational Rehabilitation. Every state has one. The quality of service varies from state to state, but the general purpose everywhere is to keep people working to their greatest potential for as long as possible. In some states, Voc Rehab will step in and fund higher education. Among other things, Voc Rehab bought me a scooter. Believe me, being in a scooter added a whole new meaning to the idea of "chasing down a story." Funding from Voc Rehab also bought me a laptop computer so I could keep up with all the other members of the media pack.

Maybe you won't need the accommodations I needed, and maybe your workplace is much more hostile than mine was, but Voc Rehab is a resource to help you stay on top of your game in the employment world. Don't wait until you need them to call them. Check them out now just to find out what they might be able to do for you in the future.

Looking to the future

It's really impossible to plan for every contingency. After all, none of us planned to get MS, right? With new medical technologies I suspect people will be diagnosed at younger and younger ages. At the very least that will give people more time to do financial planning.

Whether you're a young professional or working at a fast food restaurant, even if you're not working at all, it can never hurt to talk to a financial planner. (Many banks have them.)

I won't give you any more advice on the subject, except this: Learn as much as you can about insurance and savings plans. Decide what is best for you. Once you have a plan, try to stick to it. It's always a good idea to put money away for a rainy day, even if it's already raining.

There are other future things to consider, too, like your living arrangements. Maybe you live in a two-story house with steps up a long steep lawn. Right now those things may be fine, and there's no reason to change anything. But if you decide to move, for whatever reason, plan ahead. You might not always be able to climb steep stairs with ease. You might want to take a leisurely look at one-story houses. Look for things like wider doorways and large bathrooms. A neighborhood with nearby shopping and public transportation could be a real boon. After all, suppose your partner breaks a leg? Or your mother develops a really bad back?

Managing public perceptions

I've actually had people argue with me about my health as I've left my car in a handicapped parking spot. I'm often walking, sometimes planning on using the scooters some stores offer customers. Then I get ugly comments about how I couldn't possibly be disabled. Although I want to be rude back, I usually ignore these people or thank them for complimenting me on how well I look.

That phrase, "But you look so good," just may be the bane of my existence. I've also had trouble with "How are you?" Most people who ask "How are you?" only sort of want to know. I usually know who really wants to know and who is just offering a casual greeting. I tell people who want to know how I feel. I usually say to all the others, "Today is a good day," if it is, or, "I've had better days, thanks, how are you?" That way, I'm giving the person an easy way to get to what he or she really wants to talk about. It usually isn't my health.

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