Straight talk for those newly diagnosed with MS

What I've learned over decades living with MS.

by Debbie Petrina

In the beginning

I was 25 years old when multiple sclerosis became a part of my life. It was the 1980s — the MS dark ages. No social media, no cell phones. A calculator sat on my work desk, not a computer. The letters "MS" were obscure. Neither my house nor my car had air conditioning. I didn't just feel alone; I was alone.

Debbie Petrina doesn't let MS stop her from traveling and creating new experiences with her family.

It's amazing to have lived through the MS evolution. Sometimes I hear, "So much is available to folks diagnosed with MS! Look how much information, awareness, research, treatments, support and access there is!" So true. But that doesn't make starting to live with MS easier today than it was back then.

I've been part of this MS arena a long time. Ever since my diagnosis in 1984, it's been my purpose in life to educate others about MS, especially those newly diagnosed who are entering what I dub the MS tunnel of the unknown. I try to make things a bit easier for them than it was for me.

What I learned

1. MS is manageable, meaning I'm in charge and in control. It took me a year or so to understand there are many things I can do to feel better and, thus, do better. My constant focus is twofold:

- Health and wellness: Keeping resistance up through food, sleep, stress management and preventing illness and infections. If I get sick, I will be twice as sick, and it will take twice as long to recover.
- Treatments/medications: Disease-modifying therapies (DMTs) to slow progression, steroids to shorten relapses and reduce inflammation, and medications to ease symptoms.

2. I don't take more than one or two medications prescribed or changed at the same time. It's confusing to know what medication is doing what. I review each medication

with a pharmacist; it's another opinion, and drugs are their specialty. I never assume my five doctors are coordinated with my status. Sometimes, they aren't.

3. I'm cautious of opinions (doctors included) about my type of MS or what the expected course will be for me. There's no crystal ball, and every case is different no matter what "the trends" predict. My first and second relapse, three years apart, were like night and day.

4. I've kept a detailed journal from the beginning to identify my disease patterns and learn how my body acts and reacts. In the early years, it helped to jot notes in a 12-month calendar with large blocks for reference. This is how I discovered that my MS reacted to my menses.

5. Before a doctor appointment, I type a list of questions/things to address and make two copies—one for me and one for the doctor. Items not covered during the appointment can be followed up later via patient portal or phone call. My doctors like this.

6. I must trust and feel comfortable with my healthcare professionals. If I do not, I fire them. They're necessary for medications, advice and consultation, but I have the last word.

7. My best source of comfort and information has always been an MS peer. I'm selective with whom I chat. My MS circle of friends include a few from 35 years ago.

8. Everybody has advice about what they've read or heard. I'll always listen, but with common sense.

9. Two heads are better than one. I rarely make decisions from a single source of information. This includes anything I do in life.

10. When in doubt about something, I say "no." I can always reconsider later.

11. Despite my independent nature, I welcome support from others — even strangers — whether I need it or not. It's beneficial for all of us.

12. I embraced using a variety of mobility aids to keep moving forward with life. Canes, rollators and scooters provide safety while preventing excessive physical stress. Driving with hand controls and getting upstairs using a stair glide were liberating.

13. I sought mental health therapy numerous times to help me through difficult emotional situations. It saved my life.

In the end

Despite the challenges MS threw at me, life has been terrific. I have survived MS, 44 years of marriage and motherhood. I'm still the family matriarch. My home is filled with photos and

mementos of my achievements and travels. I give credit to my love of reading, swimming and interacting with people for my mental and physical wellness.

Debbie Petrina and her husband

I use a wheelchair now, but it has never held me back from anything I wanted to do. I bought my first scooter in 1987 although I was still walking. I'll always remember a guy in an amusement park asking where he could get one for his pregnant wife! Today, I'm mostly independent. Newbies nowadays have a great prognosis due the progress of DMTs.

During my long life, I realized that life in general is like MS — unpredictable and individually unique. Stuff happens. I experienced job losses, long-term disability, family deaths and severe injuries. I found ways to feel better and thus, do better.

Although I didn't have a choice about getting MS, I did have a choice about whether I was going to let it control me or manage my life. You can, too.

Debbie Petrina lives with her husband in Glendale, Arizona.