

## **Tipping Point #1: Diagnosis**

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Can anyone forget the exact moment when you learned you had MS? You had known there was something wrong but this was the moment when the diagnosis was confirmed. You had a disease that, even if you didn't know much about it, you knew was really serious. The initial uncertainties associated with how your life might be affected by MS must have deeply shaken you. This was, indeed, a tipping point. In such a situation it is much easier to avoid thinking about ramifications, to not allow yourself to picture how your life and plans may change.

Why dwell on negativity? Isn't positive thinking supposed to help disease management? Well, yes, it actually is—but sticking one's head in the sand does not constitute positive thinking. Taking the actions listed below may initially scare you because you will learn so much about your disease but we also believe this knowledge will ultimately empower you. We believe that taking these steps may lessen the emotional and financial impact of MS when, and if, changes in abilities occur. You don't have to tackle them all at once. Take a breath and work on them gradually while you adjust to any changes you may be experiencing.

1. Learn as much as you can about MS. Yes, you will learn about symptoms and prognoses that may never be part of your MS, but it is better to be prepared than to be surprised by an unexpected development in your disease progression. There are great websites containing valuable information that will help you understand your disease. These include the MS Foundation, the National MS Society, MS Association of America and the Rocky Mountain MS Center. Our website has links to all of them. Go to [www.msqjp.org](http://www.msqjp.org) and click on MS Info. In addition, our case managers at MSQLP meet with those who are recently diagnosed. We can discuss the disease with you and identify ways in which our organization may help. All our services are free. Call our office (831) 333-9091 if you would like a consultation.

2. Start a medical file that is updated continuously. It should include:

- A copy of your MS diagnosis written by a physician (it may be written on a script pad). You may need this as support for future claims for financial and social service resources.
- Copies of MRIs – they are usually given to you on disks.
- An updated list of medicines you take regularly, including any herbs or supplements in your regimen.
- Information you wish to share with your doctor—a list of symptoms you exhibit, concerns you have, etc. While not everything you experience as a symptom will be due to the MS, it may take some time for you to

discern which ones are MS-related.

- Private healthcare insurance, Medicare, or MediCal information (ID and group plan numbers, e.g.)

Take this medical file with you to all health care appointments—and don't forget your dentists. Some medicines may cause dry mouth and other problems that your dentist should know about. Bringing your file with you will ensure that your doctors have your most up-to-date information and that you don't forget any issues you wish to discuss with your physicians.

3. Consider beginning a relationship with a comprehensive MS carecenter (in our area there are two: one at UCSF in San Francisco and one at Stanford University in Palo Alto). There are advantages in having their clinicians know you and your MS from baseline. Even if you can only go once per year and are followed locally by a general neurologist for prescriptions and exacerbations, the opportunity to learn about MS and be cared for by experts who see hundreds or thousands of patients a year can be a good thing. In addition, in some (not all) parts of our service area, local neurologists will not prescribe the most common MS drugs.

You may need to go to the MS centers to become part of these programs. Check with your own neurologist. Finally, many of our local neurologists have used the MS centers for second opinions in the initial diagnosis phase and have worked with them when determining if there is a change in your diagnosis (from one category of MS to another).

Having said this, some of our clients have reported challenges when working with the MS centers: records getting lost, trouble getting prescriptions filled, difficulty getting appointments in a timely manner. So keep expectations realistic. There are always advantages and disadvantages when dealing with large institutions and the MS centers are no different. One important note, however, if you decide to use an MS center be sure you sign releases so that information flows between your local neurologist and the MS center.

4. If you and your neurologist have decided to participate in one of the major MS drug programs (Avonex, Betaseron, Copaxone, Rebif or Tysabri), be sure to take advantage of the support systems provided by each of the programs. These include nurses who will speak with you on the phone or come to your house to address specific needs. There are also phone or online support groups for many of these drugs which may be a great resource regarding side effects, use techniques, etc. The drug companies sponsor some of these support groups; others are independent.

5. If you have private insurance (not Medicare or MediCal), contact your

insurance company. Ask if they will assign a case manager to handle all future claims (you'll need to tell them that you've been diagnosed with MS). If they will, this will make your relationship with your insurance company easier because there will be one consistent person with whom you speak regarding benefits and claims. He or she will become familiar with your needs. We need to add a caveat here.

If your insurance is provided through your work (especially if you work for a small firm) you may want to consider the ramifications of disclosing your medical status—see Tipping Point #3 about employment.

6. Although you may not need to use all of the services provided by your insurance company, carefully review your insurance plan's coverage in reference to: doctor visits, drug coverage, durable medical equipment (this identifies which, if any, medical equipment your insurance will cover—everything from a cane and a commode to a motorized wheelchair), home care provisions (Will they pay for skilled nursing facilities, assisted living facilities, or visits from such agencies as Visiting Nurse, and if so, how many visits in a year?), rehabilitation services (How many in-patient and out-patient visits in a year?), and mental health services (How many psychotherapy or counseling visits in year?).

This is among the most important information you can have. It identifies your entitlements. Make sure you understand what each section of your policy actually means. If you are unsure, call your insurance company's benefits department for clarification.

7. Attend educational events about Multiple Sclerosis. MSQLP offers one or two per year, as do the National MS Society, MS Foundation, MS Association of America and pharmaceutical companies. At these events you will learn about the latest MS research, drug programs in the works or those that are newly released, information about treatment of specific symptoms, and more. Most offer Q & A sessions so you can have your own questions answered. One great thing about these meetings is that the tone is usually quite positive. We are getting closer to answers. Our newsletter identifies many of these events.

8. Attend an MS support group. Although this may be difficult if you have recently been diagnosed because you may meet people who have a more advanced stage of MS than you, remember, this is the one group of people who completely understand what you are going through. They have been there before you. They have experienced what you have experienced.

They are there to provide emotional support to each other. No one else will quite understand the way that they will. There are MS support groups

throughout the Tri-Counties. MSQLP sponsors four: two in Seaside (one for persons with MS and one for caregivers), one in Santa Cruz and one in Salinas. National MS Society sponsors one in Monterey and one in Santa Cruz, and one in Hollister. Meeting times of all these groups are listed near the end of each newsletter.

9. Learn about MSQLP's Supportive Therapy program. This program's group sessions (one session per week for 8 weeks) offers participants a chance to work on the feelings they have, the challenges they face and how their MS affects their relationships. Call the office to learn more about our program and to discuss whether it might be appropriate for you.

10. Identify the members of your personal support group. Who among your friends, family and acquaintances try to understand what you are going through? Who is supportive in a positive way? Who listens while also challenging you to be the best you can be? Who helps you make choices that may not support what others want but are best for you in the long run?

With whom do you feel comfortable? Who will join you in a frivolous moment when frivolity is needed? These are the members of your personal support group. It may be small or large—either way, recognize and cherish them. They will be your rock as, hopefully, you are to them. Talk with them about your MS and its challenges. Share what you think, know and believe. Listen as well. If any member wishes to attend a caregiver support group meeting, encourage them. It will give them a chance to talk with others who support persons with MS. Share your written and online resources with them; information will empower them as well as you.

11. Agencies that may help explore issues related to this tipping point:

***Information about MS:***

- MS Association of America: [www.msassociation.org](http://www.msassociation.org)
- MS Foundation: [www.msfocus.org](http://www.msfocus.org)
- National MS Society: [www.nationalmsociety.org](http://www.nationalmsociety.org)
- Rocky Mountain MS Center: [www.mscenter.org](http://www.mscenter.org)

***Local MS Care Centers***

- University of California at San Francisco (UCSF) MS Center: [www.ucsf.edu/msc](http://www.ucsf.edu/msc)
- Stanford University MS Center: <http://neurology.stanford.edu/divisions/ms.html>

***Support Services for Major MS Drug Programs***

- Avonex Services: [www.avonex.com](http://www.avonex.com)

- Beta Plus (Betaseron): [www.betaseron.com/patients/betaplus](http://www.betaseron.com/patients/betaplus)
- Shared Solutions (Copaxone):  
[www.copaxone.com/supportservices/default.aspx](http://www.copaxone.com/supportservices/default.aspx)
- MS LifeLines (Rebif): [www.mslifelines.com/global/about-ms-lifelines.jsp](http://www.mslifelines.com/global/about-ms-lifelines.jsp)
- Touch Prescribing Program (Tysabri): [www.tysabri.com](http://www.tysabri.com)

## **The Best Thing I Did When I was First Diagnosed with MS . . .**

*Marilyn Howell, MSQLP board member, Marriage and Family Therapist*

The best thing I did when I was first diagnosed with MS was listening to my husband. To me, hearing the words that I had MS set off a bomb inside me. I envisioned the absolute worst scenario—I would soon be in a wheelchair, I could not work, I couldn't live the life I had at the time of diagnosis. Basically, I believed my life was over. But, gradually, my husband's words began to make it through the negative curtain I had drawn over my future. He looked up statistics about MS and started feeding them to me. Two-thirds of people with MS remain able to walk, although many will use assistance. New drug programs are making great strides in slowing the rate of degeneration. Most people with MS have a normal or near-normal life expectancy.

Over the next months I began to understand that my life, although changed, was not over. For example, I did not realize that I was in a flare-up as I was walking around, running into walls, while the room spun around me from my vertigo. My doctor hadn't told me. What I needed was other people with MS to talk with and there was no support group where I lived at the time. That's why I am so passionate about MSQLP. I needed their services in 1998 but they didn't yet exist. I had to go hunting for help on my own. I found a psychiatrist who had MS. I went to see her to find out how I could continue my work as a therapist when I had MS. She helped me in many ways but mainly she helped me grieve about my diagnosis. You need to grieve so you can move on. And she was the one who told me I was in a flare-up.

It's funny, I now look back on—MS can certainly throw the unexpected at you. I had to emotionally recognize that I am a person with MS but that is not the only way to define me. I am much more than my disease. My advice? Figure out how you can do what you want to do—and then do it.