

Dear Gary and Lisa Part I: The Early Years



The following letter is written by 55-year-old me, who has been living with multiple sclerosis (MS) for 25 years. It is written to my very scared 30-year-old self and 25-year-old partner, Lisa, one week after my diagnosis with MS in 1995...

Dear Gary and Lisa:

A week ago, you learned the true identity of the uninvited guest who arrived on the day of Gary's 30th birthday. You are in the prime of life, and then out of nowhere come, this freight train barrels along your track. No one deserves this.

MS affects each person living with it in different ways. MS will progressively cause more and more damage to Gary's brain and spinal cord, removing physical, sensory, cognitive and bodily functions piece by piece. There is no cure for MS, no way to bypass it. You have been crying yourselves to sleep every night since the diagnosis. Yes, "this really sucks," is an appropriate reaction.

Lisa, you have always been very calm and resourceful. At a young age, you could have been left on an unknown street corner and successfully found your way home. You are now with Gary on a new unknown street corner, and neither of you has a clue which way to go. You will never return to the same home again. Your path through life changed last week. You will need to find your own new path through life. And Gary will need your help finding his.



Lisa and me on our wedding day

You are both overwhelmed with questions. What will Gary's future course be? When will a walking cane, walker or wheelchair enter his life? Should he continue education? How long will he be able to work? Should he target a different career path? Should you plan for Lisa being the only income earner? What medication decisions need to be taken?

I am writing to you both 25 years into your future. I am going to provide a set of experiences and lessons learned with the goal of short-circuiting this learning process, making sense of what is happening, and better preparing you for the journey ahead.

Never Cry Alone

The emotion in both of you is very raw at the moment. This peak of emotion will pass, though it will remain just below the surface for a long time. Lisa had the idea very early on of us agreeing not to cry alone. When the raw emotion begins to surface, do all you can delay it until you are no longer alone. Too much crying alone will lead your mind to places it should not be. Crying together will help share the burden, reduce the negative, and help you better prepare for what is coming next.

The Five-Year Daze

While the circumstances are abnormal, your initial reaction is normal. Gary, you will not be yourself for a while. In conversations with friends and family, your mind will easily drift to a different place. Every minute, every hour, every day your thoughts will be consumed with trying to come to terms with this illness, trying to make sense of the subtle changes already taking place in your body. You will try and act normal, not letting the outside world know what is consuming you. You will grieve the life that has been lost. You will seek alternate explanations for what is going on. This initial daze will last 5 years. Get used to it.



The Prediction Formula

Your near-term obsession, Gary, is with learning as much as you can about MS. Your obsession is feeding one goal – trying to predict what is going to happen. You are reading studies on the natural history of MS to see if any of what you are experiencing now can predict what the future course of the disease will be. Most newly diagnosed with MS will do the same thing. I am going to short-circuit this research for you: there is no formula that will predict what is going to happen. MS runs a different course for every person living with it. However, while the future course of the disease is not easily predicted, personal behaviors you take on can improve the outcome compared to where you would have been without taking them on. More on these behaviors in a future letter.

Medical Appointments

Being the naive and indestructible young people you are, you have elected until now to bypass obtaining health insurance. In time you will learn how to navigate this labyrinth from first obtaining insurance and then knowing the difference between in-network and out-of-network, calculating deductible and co-insurance, assessing a formulary, and the importance of pre-authorization.

There will be many MS-specific medical appointments. At times, they will be frequent. Lisa attended all those appointments, not because I needed her to be there, but because she wanted to. MS is something that will affect you both. Much of the effort of normal life can fall to the care partner. The care partner has just as much a stake in those decisions. They may be the first to detect improvements or worsening or notice side effects from medications or other forms of therapy. Medical providers will value the insight and perspective of a care partner. And if cognitive deficits enter, the care partner will be the memory bank of medical discussions and will help think through the rationale of any medical choices needed.

Editor's Note: [Read part 2](#) of Gary's letter.