

Dear Gary and Lisa Part II: The New Pattern of Life



Dear Gary and Lisa:

In the [first part of my letter](#), I alerted you of what's to come in the early years of my diagnosis. With the passage of time, what was once abnormal for you both will become normal. Daily adaptations to new and old symptoms of MS will become routine. A new pattern for life will emerge. This second letter will describe this new normal.

The Only Certainty Is Uncertainty

Gary, you will learn that you can be OK one month, then the next be overwhelmed by fatigue or another MS symptom, with no certainty on when or if ever you will return to baseline. This uncertainty is difficult to plan for. Continuous uncertainty is your new norm. Plan for the worst; expect the best.

Medication - Balancing Benefit and Risk

Your first big decision is which of the many disease-modifying therapies (DMTs) to take, or none. Each option presents a differing benefit, side effect and administration profile. The science behind which option will work the best remains very inexact. All DMTs have side effects. Several will scare you. Some require frequent self-injection, which could repulse you. You will need to balance the risk of losing function (which is high) against the risk of the

medication's side effect (which is usually low) along with your tolerance of the method of administration. Electing no DMT escapes the side effects, but leaves you unprotected. Each option represents the good and the bad. Balance the clear benefit against the possible risk.

Friendship Circles

Your friendship circle will grow smaller over time. There are those who will slowly move away from you. Gary, your confidence in yourself will be reduced, and you will become more hesitant to develop new friendships out of concern of not wanting to burden them with this information. The friends that remain, though, you know are true friends. Over time, you will develop a whole new circle from amongst those also living with MS. These are people you will instantly connect with through shared experiences and stories. They will unconditionally want the best health for you.



My family

The Camel's Hump

Popular belief holds that a camel stores water in its hump to allow it to go without drinking for long periods of time. With MS, the camel's hump is your body, Gary, and the water is good health. Good health is stored in your camel's hump through medication compliance, exercise, diet, proper sleep and other mechanisms. When a relapse occurs, you will draw on that camel's hump of good health to sustain you during and after the potentially permanent damage to the brain and spinal cord. The healthier you are before any relapse occurs, the better you will be when the episode ends. And you will not have to start at ground zero to rebuild strength.

The best way to store health is to remain in motion. Find activities to do which you enjoy - if you do not enjoy them you will not keep doing them. Constantly challenge yourself physically and mentally.

Never Forget the Care Partner

Gary, you will be able to count on the fingers of one hand the number of people who will ask Lisa how she is doing with your condition, and they will have a special place in our hearts. Much of the burden of living with MS can fall to a care partner, and depending on the course of the disease, that burden can be intense for short or long periods of time. There will be periods of time where Lisa will need to drive you to work every day – with a baby in the back seat. There will be times when you will be traveling together with two young children where she will be the one carrying all the luggage. You should never forget the care partner.

Career Path

MS occurred in the prime of your life when careers are being firmly established. A thought that will dominate your mind in these early years is whether you continue to pursue career dreams or throttle back a little. It is a difficult decision. Eventually, you will elect to throttle back. The career path you had planned would require long work hours and much time away from home. Today, medical options have become better at managing MS, which makes it easier to wait to throttle back. However, this type of decision remains your joint choice to make.

Editor's Note: Read [part 1](#) and [part 3](#) of Gary's letters.