

Mothering alongside MS



My disease and my daughter have given me a new perspective on life.

by Sara J. Winston

When you're young, you see only what you want to see. No one can get in the way of the fairytale. And then, suddenly, there are no guideposts, no bumpers to guide you through difficult periods.

This platitude applies to two experiences I've had in my life, both of which, in vastly different ways, have been the impetus for my perspective to change: learning to live my life with relapsing-remitting multiple sclerosis and learning to be a mother.

I was diagnosed with MS in 2015. The diagnosis came just before a long period of double vision and intermittent blindness when I was in my early 20s. Before that flare, the risks of MS seemed somehow abstract and distant. But I'm a photographer — my waning vision was an unimaginable hardship. During those months, I could only see the world clearly when I used the autofocus functions of my camera to view things far away from me. At the same time, I began to feel the weight of my diagnosis and the uncertainty of life with more clarity than I ever had before. Recovering was a long road, both physically and emotionally. I felt very alone.

But I did recover, and after a lengthy period of remission from any symptoms, I found out that I was pregnant. My husband, Topher, and I decided to become parents.



Winston was diagnosed with MS in 2015. She has been learning how to take care of her daughter, Anita, while also taking care of herself.

I stopped taking Tysabri from January 2019 through November of the same year. My daughter, Anita, was 3 months old when I had a burst of physical symptoms that reminded me of the reality of my disease. An alarm sounded that I needed to resume infusion therapy. The experience of not being able to hold my infant daughter due to weakness was frightening. I was beyond relieved when the symptoms were at bay and my body returned to a stable state of remission.

Not alone

But then new and urgent questions arose: How could I protect my child while protecting myself from relapse? How could I maintain a calendar for my child's care and for myself? How could I be a good role model for my growing child while living in fear of my next recurrence of symptoms, which could come at any point in time?

These questions have never really gone away but their urgency rises and falls each month, like the crest of a wave, in sync with my Tysabri infusion, which is akin to a preventive care regimen. It's been helpful to remember, time and time again, that I'm not alone in caring for my daughter, nor in caring for myself. My husband and mother have been steadfast anchors along this journey. In the early days of caretaking, both of myself after my diagnosis and of my daughter during that first bout of postpartum MS symptoms, it was much harder to remember I had people in my corner. I again felt so alone. During moments of stress, hardships make it much more difficult to see the source of light and hope.



When hardships hit, Winston reminds herself that she has people in her corner, including her mother and husband.

The truth is, we do the best we can with what we have. Everything is unknown and fragile. There were never any guardrails. I do not feel fear in this acknowledgment, but rather I feel it more as a mercy.

Photographs as commemoration

I have been photographing myself at each Tysabri infusion since I began receiving the medication in 2015. Similarly, I've been photographing us — my daughter Anita and me — at every pediatric visit, both the predetermined benchmarking well-visits and all the visits for an illness.

In the pediatrician's office, once she had the language, Anita began to ask: "Mama, why do you bring your camera here? Why do you photograph us each time?"

So far, I've said something like: "I want to commemorate these moments, I want to see how we change. I want to hold onto a record. I want to hold this moment, this memory." Yet each time she has asked, my answer has evolved.



Being a mother has influenced Winston to look at her relationship with her own mother, who has been a support system for Winston during her journey with MS.

Becoming a mother has made me see my own mother differently. This seems to be the natural order, yet the revelation came into focus slowly. I was always aware of the myriad ways that my mother wished to protect me from many of life's evils and ills, especially when the most difficult period of my illness in my 20s marked the end of my youth in an instant. She tried her best, yet she did not know how to see me into the next phase of my life — the one after the fairytale — the phase of chronic care for multiple sclerosis.

I want my child to see us beyond the fairytale. I don't want to disrupt the natural flow of her wonder and curiosity. I also want her to see her mother's strength and adaptability, the resilience we share, the agency and power that she contains. It's important that I not only try to temper my child's emotional woes but also try to teach her, early on, about her own strength by showing her mine. She can see it in the photographs I take of myself and the photographs I take of us together.

Photography has been a practice and a ritual in my life for nearly three decades. It has allowed me to see beyond fear. To see myself. To show my daughter strength.

Three generations

This upcoming Mother's Day, I hope to make a portrait of three generations together — my mother, my daughter and me — to share in the strength we carry matrilineally in spite of all that is unknown.



Winston hopes her photographs bring her and her daughter strength through adversity.

I believe in the power of photography to remind us of the care of those closest to us that can too easily be forgotten. I believe in the power of photography to communicate that which cannot be said with words. I can, of course, say I love you, you are strong, you can do hard things and I'm proud of you. Yet, the picture allows that feeling to exceed language and be shown — and hopefully — felt from the inside. It allows me to remind myself, too.

Sara J. Winston is an artist and writer based in the Hudson Valley region of New York. She is visiting artist-in-residence and photography program coordinator at Bard College.