Decision Time: COVID-19 Booster (Additional) Shot & MS



I just emailed my doctor about getting a booster shot since it just was authorized by the FDA last week for people with compromised immune systems.

I live with MS and am immunocompromised because I take Kesimpta, a once a month shot that depletes the B cells in my immune system. B cells are what fight viruses in your body. Once a month, I give myself a shot that targets and "blows up" the B cells in my immune system. They start to regrow and then it's time for my monthly shot again and BAM the medicine goes in and blows up any new B cells that had started to regrow.

At the start of the COVID-19 pandemic, my neurologist and I discussed how to proceed. He felt pretty confident the vaccine would be available to immunocompromised people sometime between March to May (at the time, he was just estimating based on what he was seeing and hearing). We decided I would stop my Kesimpta treatment in February 2021 so that my immune system had time to rebound and start re-growing so that when the vaccine did become available to me, I would be in a position to get it immediately. By stopping my Kesimpta injection, there was a possibility that my MS could start progressing. I decided it was worth the risk, that even if my MS might get worse, I'd be safe from the pandemic.

My husband and I got vaccinated in April 2021. I cannot articulate the relief it brought me after hiding inside for over a year.

In July, I heard from a lady who has MS that she had no antibodies to COVID-19, even after

fighting and surviving it and being vaccinated afterwards. I asked for an antibody test (I have heard that it's not a full picture of your immunity, but my neurologist said it's the only test available to measure it at all). My antibody test showed I had little to no antibody response to the vaccine.

I get nervous being out around people right now, especially with the Delta variant being so aggressive. I get anxiety for myself and my kids. I look at people and wonder if they have been vaccinated. Do they look at COVID like it is a threat? Are my kids keeping their masks on correctly at school? It's so hot in California right now, I feel suffocated when I have them on sometimes.

I feel like I only have two options right now:

- A. Once again pause my MS treatment for 4-6 weeks so that my immune system rebounds enough that I can safely get the booster shot and hope that it gives me more immunity this time.
- B. Hide inside until this is over.

The stress and anxiety I felt last year when the world shut down was intense. My family lost someone to COVID that was very important to us. The fear I have of getting COVID is magnified – I have ended up hospitalized with pneumonia from what started as a cold my kids brought home from school... TWICE! I imagine with COVID, there is a very real chance I might not be able to fight it off and could die. It's exhausting to hear people still call it a hoax after all this time.

I have no easy choices in this situation. This is how it is living with a chronic, incurable disease. I have to make endless choices every day that affect my life in big and small ways.

Sometimes they're easy choices, like pizza or Chinese takeout? Lately, it's been about who I might be around; do they wear masks? What's their take on COVID? Are they vaccinated? Other times it's really horrible choices like, is it worth possible disease progression or even possibly death?

I already feel like I miss out on my life somedays because I live with MS. It's really heavy to deal with the constant fatigue, the physical limitations and the lack of energy on a daily basis. The give and take of it all when living with a chronic illness. On top of it all, I don't want to die from COVID.

I have an absurd level of mental exhaustion from the last year and a half. I have been trying to stay informed but not freak out too much. I have been attempting to keep coronavirus away from me and my family. I have been keeping an eye on my kid's mental health from the trauma of living though this pandemic. I have been trying to move the constant resentment of having to live with MS to the back of my mind. I really hate that I have to rely on other people to make good, healthy choices in dealing with COVID. I don't want to have done all of these mental bobs and weaves only to end up dying from stupid COVID because I couldn't outrun it or outsmart it.

I heard back from my doctor. She said to get the additional shot on Sept. 1 - now my immune system has some time to grow some B cells.

Editor's Note: Learn more about the National MS Society's COVID-19 Vaccine Advisory Group's **recommendations on additional doses of the vaccine** along with **timing your DMT with the vaccine.**

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