

**I've Been Sick With COVID-19 For
Over 3 Months. Here's What You
Should Know.**

"One hundred days later, I've learned there is nothing 'mild' or predictable about this disease."



COURTESY OF ANN E. WALLACE

The author on her couch receiving oxygen in June 2020.

Today marks my 100th day being sick with [COVID-19](#). My symptoms began on March 17, two days after I [published an essay on HuffPost Personal](#) about facing difficulties getting my 16-year-old daughter Molly tested for the virus.

Despite the strict criteria for testing in my home state of New Jersey at that time, Molly and I were finally both tested on March 22 because we were deemed high-risk: me, because I have multiple sclerosis, and Molly, because she had been displaying symptoms for two weeks and was therefore a health risk to me.

Back then, two weeks sounded like a very long time to be sick with COVID-19.

We had no idea.

From the start of our journey, I've shared our experiences on social media and via various publications in the hopes of helping others navigate the uncharted waters of this virus. Reliable information about everything ranging from risk factors to testing facilities was difficult to find in March, so I knew that whatever I learned could be valuable to others.

Since I started speaking out publicly, many people have reached out to me with concerns about their own health. Others, who are sick with COVID-19 themselves, wanted to relay their own experiences. As the rates of infection begin to surge again around the country due to many states reopening businesses, as well as individuals and groups who refuse to wear masks and practice social distancing, I want to share four somewhat common and, honestly, remarkably upsetting sentiments that I've recently encountered.

1. "I'm afraid to tell people that I have COVID-19."

We need to drop the stigma that comes with having COVID-19. Shame serves no one, and, if you are sick, you may need a large network to support you. I know this firsthand: For week upon week of my illness, I was not capable of preparing a meal or doing a load of laundry. Even speaking was difficult because it required oxygen I did not have. Three months in, simple tasks can still make my oxygen levels drop and leave me short of breath. Now is not the time to choose privacy; even though you should not be near other people while you're sick, you may need them to provide you with food or medicine and run errands for you.

More important, because COVID-19 is a novel coronavirus, we are all still actively learning about it, and any new information we receive can be hugely important — that includes scientific studies, but also personal anecdotes too.

You never know whose life you might affect, or even save, by sharing your experience. If you're too embarrassed or ashamed to tell your story, you could be missing an opportunity to help others. I have had many health problems throughout my life — from fighting ovarian cancer in my 20s to being diagnosed with MS before I turned 40 to, now, COVID-19, which caused me to spend my 50th birthday in the emergency room. I study, teach and write about illness, and I live by the belief that our stories matter.

2. “My COVID test was negative. Now what? People don’t believe I’m sick.”

First, it’s important to understand that as many as 15-30% of COVID-19 tests performed may return a false negative. What’s more, many experts believe that tests are most reliable when done between three and six days after symptoms first appear. Many people, especially in areas where tests are not readily available, are unable to get tested that quickly.

If you suspect you were infected or have symptoms, do not delay in getting tested. A positive test result will make your life easier in a multitude of ways, from securing priority treatment, sick leave from work, inclusion in long-term medical studies that may help find a vaccine or better treatment for the disease, and, quite frankly, the right to be “counted.”

But, if your test comes back negative, do not assume the test is correct. By the time my daughter was tested, she was on day 15 of her symptoms and her test results were negative. By that point, she had already shed most, if not all, of the virus, even though she had another week of symptoms to fight through. Fortunately, none of our doctors believed her test results, but we might have been tempted to believe it if my test (given the same day as Molly’s, but on day five of my symptoms) had not been positive.

I know many people who have “presumed positive” cases, who had symptoms and were aware of having been exposed to COVID-19, yet who were not able to get tested or received negative test results. Absent a definitive test, other possibilities need to be ruled out, but do not hesitate to push your health care provider to do that work.

3. “It’s been two months. No one believes that I’m still sick.”

I’ve been fortunate that no one in my network has doubted that I’ve been sick for this long. For three months, I have been sharing my story online, and I suppose my friends don’t think of me as the type to orchestrate such a finely wrought long con.

The fact is that many COVID-19 patients are sick for months, and they are struggling to educate others about this reality even as they are navigating daily life with a terrifyingly relentless, debilitating and deadly disease. Believe them. Their stories are true and they are more common than you probably expect.

Due to the lack of robust scientific information about COVID-19 or the difficulty of finding reputable sources for it, patients are sharing their experiences and compiling data through online

support groups, such as the [Body Politic COVID-19 Support Group](#) and the [Long Haul COVID Fighters](#) on Facebook. It is becoming increasingly clear that those experiencing the long course of this disease, dubbed “long-haul” patients, [tend to be younger and otherwise healthy](#). Even though I have MS, my autoimmune disease does not limit my life. Prior to contracting COVID-19 I was active and fully ambulatory, worked a demanding job, and was fortunate to have what I consider above-average stamina.

I recently joined the Long Haul COVID Fighters group, where there are over 4,000 members who have been sick for 80 days or longer. Others in the group are marathoners, dancers, fitness buffs and parents of young children. These are not the types of people we hear about as being especially susceptible to COVID-19.

It’s time to dispel the myth that the coronavirus is just a bad flu that only kills older individuals who were near death anyway and that everyone else recovers quickly. Neither of those claims is true. Those who do not survive COVID-19 cannot be easily lumped together or dismissed.

What’s more, there is a huge swath of people who fall in the middle of these extremes and who are sick from four weeks up to several months.

Most of us long-haul patients have been diagnosed with “mild” or “moderate” cases because we don’t need intubation or prolonged hospitalization, but don’t be misled by that. Just two weeks ago, I was in the ER for the fourth time with reoccurring flulike symptoms and an uncomfortable tingling in my arms and legs. A few days later I had the energy to work in my garden for several hours, but two days after that I almost passed out before breakfast. When I checked my blood oxygen using my fingertip oximeter, I saw my level had dropped to 88.

I learned early in my illness that oxygen saturation is measured as a percentage (100 is perfect) and that any reading below the low 90s might warrant a trip to the emergency room for supplemental oxygen. After weeks of dropping levels, I was able to get an oxygen concentrator at home, so I can now turn on the machine, insert the nasal cannula tubing, and rest on my couch until my level has rebounded. For me, there is nothing “mild” or predictable about this disease, even three months in.

If you see your employer or friends doubting or denying the long-haul course of this disease or the long-term effects, please speak up. We need your voices and your advocacy.

No one who is sick should have to worry that their boss or spouse or doctor doesn't believe them.

4. “My doctor said I have a mild case and to rest at home, but that was a month ago and I'm not getting better. I'm really worried.”

My final point — and it's an important one — is that if you or anyone you know is sick with COVID-19, you must be vigilant about seeking out and demanding the best health care.

It may not be easy to make appointments or get medical tests where you live right now. In different regions, healthcare professionals may be still, again, or newly inundated with patients.

I cannot tell you how many phone calls I have made in the past three months figuring out first how to get tested and then how to get the other tests and services that I need. The nurse case manager at my doctor's office has helped with these calls as well. Even with her help, it hasn't been easy. We have even been told conflicting information by different people at the same facility. In fact, in April I lost valuable time when I followed a hospital's very specific

instructions and went to an ER for a preauthorized CT scan ordered by my doctor, only to have the ER doctor decide that I didn't need it and send me home.

Two weeks later, I got the test at a different hospital as an outpatient. A nurse met me, with my oxygen tank in hand, at the curb, put me in a wheelchair, covered me a sheet from head to toe, and wheeled me directly into the CT room. I could not enter the building unescorted, I could not use the restroom, I could not see where I was going, but I got the test.

The point is you need to be vocal and persistent about what you need, even if you aren't entirely sure what that is. COVID-19 can seem or start off mild but it can worsen quickly and become deadly in just a matter of days, so be proactive. Your primary care doctor should be helping you. If he or she is not, I cannot say this firmly enough, *you need to find a new doctor.*

COVID-19 is nowhere near done with us, and our leaders and neighbors are not necessarily making decisions with your health as their top priority. If they were, we would have widespread free testing, health care support, and contact tracing in every town in the nation. If they were, we would not have people coming to blows or worse over mask-wearing requirements or closed bars and restaurants.

Until that changes, be prepared to advocate for yourself and your loved ones. It could be a matter of life and death and your life is surely worth it.

Ann E. Wallace, PhD writes of her experiences with cancer and MS, motherhood, love, and the realities of living in contemporary America. She has a new poetry collection, "Counting by Sevens," available from Main Street Rag. Her recently published pieces in journals such as Mom Egg Review, Wordgathering, Snapdragon, Riggwelter, and Rogue Agent, can be found on her website AnnWallacePhD.com. She lives in Jersey City, New Jersey, where she is an English professor at New Jersey City University. You can follow her on Twitter [@annwlace409](https://twitter.com/annwlace409).