Karen's COVID story

It all started one Tuesday afternoon with a slight tickle in my throat while working from home. "Probably just allergies or a bit of dry air," I thought dismissively, not imagining it could be anything more. Early Wednesday morning, the congestion had settled in and I thought, "Well, it's probably that head cold that's been going around the kids' school." I then stopped myself short. It had struck me that I had made plans that Saturday to visit my mother in southern Maine. While I thought at the time that COVID-19 was highly unlikely, I didn't want to take any risk of potentially exposing her and her neighbors. So, I immediately made an appointment at the Bangor Northern Light Health Swab-and-Go. Thursday morning, with just a minor case of the sniffles, I received the news that I was COVID positive.



A day-in-the-life photo from the Cashman COVID-19 bunker.

With the news still sinking in regarding my breakthrough

case, the Cashman COVID-19 Quarantine Plan was immediately put in action, and I was sent down to spend ten days in the "bunker," also known as the finished basement. Two days later, my eldest daughter joined me—although she was asymptomatic, she had also tested positive. And so began our days of extreme mother-daughter bonding time.

During this time, I made a conscious decision to share my personal COVID-19+ story with my network over social media to help raise awareness of the importance of testing as well as staying home when you are not feeling well. While I certainly expected some nice notes of encouragement, I was absolutely amazed by the large amount of people who came out of the woodwork to share their personal stories about COVID-19.

In most of the messages were words of gratitude for sharing my story. "You are so brave," some would say. While I didn't view sharing my experience as particularly courageous, at first it did feel like having a big scarlet "C" pinned to my chest. Many voiced that they or a loved one had gone through a similar experience, but they had been too ashamed to let anyone know—mortified that, even while practicing all precautions, they could have possibly caught this wretched virus. Some wondered, "what did I do wrong?" I think this was a common feeling for those working in healthcare, as they felt they had let "their own" down. Unfortunately, when support was needed the most, many who I interacted with said they went into hiding to wait out a ten-day penance, ashamed that they were COVID positive.

Through these stories, I witnessed friends' reflections of loneliness, despair, and shame. And, I wondered, "What is this doing to the mental health of COVID positive individuals?

I wanted to see if I could find some answers to Karen's question, but I also wondered how common that feeling of shame was. I asked my sister who had recently tested positive while attending a family reunion at a campsite a thousand miles from home. Amy was unprepared for what it felt like to sit outside her RV, 35 feet away from the rest of the uninfected family members and watch on as they laughed and shared meals around a campfire. At first, it seemed lucky to at least get to see her granddaughter frolicking about. Then it felt

increasingly unbearable as the days went on. She felt like a leper. All she wanted to do was go home and hide which was how another friend of mine felt when her husband came home positive from his medical practice. They were shocked to discover how dangerous it felt to admit that they were now in the contaminated camp. Would people ever feel comfortable being around them again?

All of their experiences harken back to playground days and being chased by a person with "cooties." It was shocking how real the panic felt as you did everything in your might to get away from the cooties kid, but it was far worse to take your turn being that cooties kid yourself and see everyone flee, horrified at the thought of being anywhere near you.

What is also striking about the COVID shame is how unexpected it was for those who experienced it. How it took them by surprise and became as central a feature and experience of the disease as the actual symptoms. They did not know this was going to be part of it, another difficult layer in this altered reality we've found ourselves in.

I took the stories of all this COVID shame back to a couple of our Northern Light behavioral health experts to ask what kind of impact it was having on our mental health and how we can work with it.

Angela Fileccia, an LCSW and director of Acadia's Health Life Resources, first explained how shame comes about. "Shame stems from having a high degree of self-awareness and the perceived 'right' and 'wrong' rules in our circles. Shame is a version of self-blame and second guessing. We may wonder 'how could I have let this happen?' or 'I've let my family/friends/co-workers down.' All of this negative self-talk can lead to feelings of sadness, worthlessness, and depression," Angela said, noting that, "At some point in our lives, all of us may experience the painful emotion of shame."

As for what to do with ourselves once shame moves in, plain awareness is where the possibility of recovery begins.

"The best thing we can do is be aware of and acknowledge the feeling of shame," says Angela. "Be open with yourself and others about how you're feeling. Then avoid the 'blame-game' – even with our best efforts, sometimes things happen beyond our control and blaming or shaming ourselves is not the solution. We tend to be harder on ourselves than others; ask yourself this: If your best friend was in the same situation, what would you tell them? If you do discover that there was something you could have done differently, acknowledge that, vow to learn from this, and then move on. This is the way to help you heal both physically and mentally."

Sheila Thibodeau, an LCSW and director of Work Force – EAP, also noted how shame preys on identity and how truly damaging this is to us. "Shame weighs on our soul," says Sheila. "We take shame to mean something about who we are as a person. This is especially prevalent in healthcare because we put a lot of pressure on ourselves and worry that if anyone sees us making a mistake, they will lose trust in us."

Sheila points out that shame's damage to our sense of self is aided by the way it blocks all sense of perspective. Our history as a competent, valuable contributor and good human being tends to go out the window. This kind of negative and imbalanced view is toxic and something we have to actively watch for to make sure it's not setting up camp in our psyche.

Therapists aren't shielded from the insidious creep of negativity. Sheila finds herself needing to do a mindset shift several times a week. "I have to ask myself, 'What can I control, and what can't I control?' If I did everything I could not get covid and I still did, then I have to recognize that it was beyond my control. And if I hold on to a feeling of self-blame and negativity, it is going to have a direct impact on my health," Sheila says.

"If I use my energy on that then I won't have the energy to do what I need to do."

Control is a hot button. As much as many of us fear not having control, as Sheila points out, the interesting thing is how liberating it is when we have the awareness to acknowledge when we pure and simple don't. "It's actually really freeing to look at what we can control vs. what in reality we simply can't," says Sheila. "I can bang my head on the wall and choose to stay in this place of shame and self-blame, or I can not bang my head on the wall and go do something else."

What a good idea. Do you ever wonder what would happen to just stand there and be the whole beautiful catastrophe that is us? Just stand there and own it all...the mistakes, the brilliance, the achievements, the failures, the bad judgments, the idiotic comments, the acts of compassion, all of it. And in that openness to imperfection and disappointment, maybe we could just get on with it.

The takeaway

- We can't control everything and when something happens that is beyond our control, we have to stop banging our head against the wall so there is vital energy left for doing something we can. It can actually be very freeing to realize something is beyond our control.

- We need to monitor for shame, negativity and loss of perspective. These are toxins and will affect our health. When we become aware of their presence, we need to comfort ourselves as we would a friend.

- We are not our mistakes. We are not the bad things that happen to us. There are so many more dimensions to us than that.

- If we have made a mistake then we need to acknowledge it, learn from it, and then take the grace we get for being human.

And finally, when we are suffering we need to tap into our good fortune: the ready access we have to people like Angela and Sheila who can help sort it all out and resources like Work Force - EAP, Healthy Life Resources and StrengthenME (which is now in partnership with Work Force – EAP).

Note: Karen and her daughter, Amy, and my friend have made a full recovery from COVID-19 and have returned to resuming a busy life among the rest of society.