

Susie Goulding (bonus content) - transcript

Hi, I'm Susie Goulding. I'm 54 years-old. I was a floral designer before the pandemic, and before I caught COVID and ended up with long COVID. I'm currently living in Cambridge. I sold my house in Oakville because it was too big and too difficult to take care of, and have relocated now in Cambridge. And I'm currently working in the film industry as a medic. I'm a single mom to one 14 year-old boy and three dogs, and I'm hoping to be able to get back to skiing this year, but not sure, we'll wait and see.

Yeah, it was the beginning of the pandemic in the first wave, March of 2020. I went to the hospital for a yearly screening. This was the week of the lockdown. Everybody was hoarding toilet paper. Two days later, I started having just a really mild sore throat. It really wasn't too concerning. Four days later, I woke up with very bizarre symptoms. That was the start of a barrage of meandering ongoing symptoms that would redefine my definition of health. I started with inflammation at the back of my head. It felt like someone, without any pain, had hit me with a baseball bat at the back of my skull. It just felt swollen and inflamed, it felt very odd, I was having difficulty swallowing. It all sort of went ear-nose-throat for the first few weeks, and then sort of dropped into my chest, where I had a cough. Then I started experiencing gastrointestinal issues. It felt like a flu and gas and strange symptoms that I'd never dealt with before, with any illness. Then a few weeks later, after that, I started having chest pain and tachycardia and strange heart rhythms and twitches in my muscles, and this took me sort of into June. At this point in the pandemic, there was very little access to testing. You had to meet very strict criteria, if you were traveling abroad, in contact with a known COVID case, or working with healthcare or long-term care facilities, you'd be able to access a PCR test. But for the mainstream of people, we were not able to get tested and were told to just handle your symptoms at home. And at that point, nobody really wanted to go to the hospital and expose themselves to potentially getting COVID. And people really didn't know about long COVID at that time, and all these bizarre symptoms. COVID was thought to be a one-week to two-week illness that you would recover from. It was supposed to be a respiratory disease that just affected your lungs. The symptoms that I was having really didn't make sense to my doctor. I had called on several occasions through this and she said well, do you have any fever? Do you have any shortness of breath? Well, you don't? It's not COVID. Don't worry, you'll be fine. In June, testing was readily available and I decided to go to the hospital to get a PCR test. And at that point, I was suffering from severe, severe fatigue, like I had never experienced before in my life. Then I started having issues with my brain, very unusual difficulties with understanding what was going on and my surroundings around me, difficulties remembering things, difficulties with the speed at which, you know, I would react to things or be able to process information. You know, I was very dizzy, unstable on my feet, and it was quite severe. I think out of most of the symptoms, the brain issues that I was having were the most worrisome, and the most, that affected my, you know, day-to-day abilities to just to be myself. So in June, I did get tested, and I had a negative test result. The doctor said, you know, we're testing well outside of the window of where you'd be able to have a positive test result, but we'll just do the test anyway. He said, you know, from the over 32 symptoms that you've said, we can assume that you probably have COVID, or some kind of post viral issue. I did get the result back the next day, and it was negative. And that left a whole host of other issues and trying to access care and being believed by people, you know. My doctor, I spoke with asked, so how was your how was your test result? And I

said, Well, it was negative, she said, Well, there you go, you never had COVID then. You'll be fine. And at that point, I realized that she didn't have as much information as I did, and that the lived experience that I had was very important and was something that she couldn't comprehend. So I was going to need to get my help from, from other places, than, you know, my doctor. So, I started a support group to speak with other people who were in a like position dealing with issues from COVID themselves, and we needed to get together and talk about what was going on. Today, it's over two years since the pandemic started. I'm still suffering from the issues of long COVID. I still suffer from gastrointestinal issues. I haven't been able to swallow properly and since this has happened to me. I lose my voice when I get tired and I'm starting to lose my voice now. I don't know if you can tell. I just moved this week and yesterday was bed bound. COVID really takes your health from you. It takes your life as you knew it and flips your world upside down. I'm very careful now with the work that I do and with how I approach my days and trying to be careful not to aggravate the symptoms that I'm living with, with long COVID. My brain, I feel like, I start forgetting words. The more that I speak, the more challenging it is. My brain functions at a certain capacity to a certain point and it's almost as if, after speaking for you know, so many minutes, I'm good, usually for an hour zoom. Or maybe today it might be half an hour, because I'm so tired from what's been happening in the last weeks from the move. And I'll start to forget things. So, I still do have a lot of issues with my brain.

Before I was a real outgoing, multitasking, floral designer, ski patroller, mom with three dogs very, you know much on the go and with endless amounts of energy. Now I have to, you know, conserve, and really look at my day and what needs to get done, and how I'm going to approach things. I have to be careful of temperature, because I now have a susceptibility to heat, a heat intolerance. So, I have to be careful where I work and what the conditions are, and, you know, be really mindful of the fact that exerting too much out will cause, you know, bad symptoms to flare. Sleep is a huge thing as well, I have to be very mindful of getting the proper sleep. And if I don't... It's very difficult with a 14 year-old boy who wants to stay up later now, and I have to go bed earlier. You know, nine o'clock is really when I should be in bed, and he wants to be in bed later and later. So I need my sleep, if I don't get my sleep, then I can hardly think. It's very difficult for me to have the mindset to think clearly, if I don't get the proper sleep, I just can't function. I start forgetting words a lot. And I forget important things. It's difficult for me to concentrate. Like being on this podcast, I can only put an earphone in one ear. If I have any sort of distractions going on in the room, it really, you know, sets me off. So it's like sounds set me off. Too many sensory things going on at the same time really just exhausts me. You know, I don't approach my daily activities with the vim and vigor that I once did. Now I just have to pick and choose what I can and can't do. And sometimes I don't even realize and I then I figure, well I guess that's going to be on the 'can't do' list for now. It's difficult to remember things, too. So I find that I get so many emails now and it's really difficult for me to get organized. When your mind when your brain is being affected, it's really, it's really difficult and adds a different level of difficulty.

The group was, started off just as a grounds for people to come together who were going through the same issues. We needed to speak with one another to try and figure things out amongst us because at that point, nobody knew of long COVID. I don't think it was even named, we call yourself long haulers. It was just it was a mission to find other Canadians who were long haulers who were suffering from COVID and these issues. You know, their symptoms weren't going away and, and we weren't getting any help. So, you know, the group quickly grew. And shortly after we started the group, the media

started asking for interviews, and they wanted to know what was going on in that, you know, because the government really didn't warn people, they, they didn't listen to us very early out. And, you know, we tried our hardest to get the word out that there was definitely a third outcome, besides deaths and recoveries, and that you needed to take all the precautions necessary to protect yourself at that time. There were no vaccines, so mask up social distance, and really be careful not to catch COVID, because you could become a long hauler. And, you know, these were symptoms that we were having that were life changing, and we were trying to warn people to, you know, really take heed and to follow the protocols and the of Health Canada, to stay at home and mask up and protect yourself as best you could. So out of those interviews, and, and things we must have done hundreds and hundreds of interviews, the group, you know, grew exponentially, and we're now at seven over 17,000 members. And through all of that, we we've connected with a lot of researchers and practitioners, people who are interested in helping people with long COVID and who are interested in the science and who are trying to help us. We've sort of become like a recruiting grounds for research where we're patient partners. We've invested a lot of time in partnering with a lot of researchers to help them you know, create meaningful research, questions and focus that's patient driven, to make sure that the research that they're doing is, is what needs to be done. So, we're very grateful that we're being included in all of this, We're advocating to the government to have a centralized system set up and for funding for researchers and for help in creating a national platform for information, and for, you know, distribution of information. You know, so many studies are going on, but then it gets lost in translation or in dissemination from, you know, the researchers to the patient, community. We're calling out for many things to happen, for practitioners to be educated in how to recognize and be able to diagnose long COVID and help their patients, point them to the various specialists that they'll need to be referred to. And, you know, ultimately, we're trying to get post COVID care clinics set up for the masses, because right now, there are very few clinics and anytime a clinic opens, it's just stampeded by long haulers and it's shortly thereafter the doors are closed. They just they've reached capacity levels. So, there's just not enough care that's out there. So we're advocates waiting for more interdisciplinary clinics for people to be able to get treatment from. Also, we're advocating for, you know, a lot more research for the brain issues of long COVID. In a survey that we did, it was over 78%, I believe, had brain fog was one of the top three issues of long COVID. And it's just, to me, mind boggling that two and a half years into this pandemic, and there's still any kind of treatment for brain injury or the issues of the brain. You know, we're really advocating for funding for brain care, and to find out what's going on for long term prognosis of disease that's, you know, in for the future might be coming to long haulers. I was very fortunate that in 2021, I was able to access care at a clinic called Pillars of Wellness that deals with brain injury, and they facilitated a three-month rehab program for me. It was an interdisciplinary approach, with five or six different clinical specialists, and occupational therapists, physiotherapist, speech therapist, acupuncturist, naturopath and counseling. And it was that hands-on therapy that I received from them, that really was very helpful. The acupuncture was very helpful for me, that doesn't seem to be getting much talk either. A lot of the issues that I have were really helped by the treatment that I got, but it was the hands-on treatment, someone really sitting down and figuring out what exactly was going on. I was having issues with reading because my eyes weren't tracking properly and you can only figure that out in person. So I did all kinds of exercises and, you know, worked with a speech therapist and how to help and deal with the symptoms that I was having. My balance issues were rectified. I was falling a lot and so those were really helped. But that kind of care is not accessible to everyone. And so this is really important, I think in moving forward, that people have access to proper

care, and especially for brain injury And the lack of accessible care for people with brain injury and adding all of the long COVID on top of what was already in need of, makes it kind of catastrophic and urgent. What's disconcerting is that this issue isn't going away. The group gets bigger every day and people keep joining our group so the numbers just keep growing.

You know, the work that I've done throughout this pandemic, and because of this group has really given me purpose to keep going. It's also given me, I think, a lot of therapy in, you know, making my brain stay active. It's a big responsibility, I feel that people really need to have a voice and it just so happens that, you know, the, the platform that we've created, gives us the opportunity to have a voice. There's a lot of people behind this group that are helping drive this, I guess, movement, if you want to call it or whatever and we're just really focused on trying to find help for everyone. What keeps me going is seeing all the people suffering in our group and, and not having a voice and then being able to reiterate their pain in their stories and to share that too with whomever I can, to tell them what is going on, has been a really important role that I've been, you know, amazed and blessed to be able to step into.

So, it's just been an unusual experience to be in the lights of all of this but amazing at the same time. Canada has some of the top researchers in the world, and they're amazing, and they're compassionate kind individuals who just want to help us and they listen to us. As much as the pandemic has taken away, I feel like it has also, you know, provided another way for me to get something out of life.

When I think about COVID, and the impact it's had on my family, and my life, it's, it's been life changing. I think of all the other families and lives that have been lost. There are many people who are much, much more in dire straits than myself. I feel lucky that I can at least manage to work a job and take care of my son, maybe not to the capacity that I was able to before. But, you know, this illness has taught me that you need to approach life with faith and with an optimistic outlook, and just be kind to yourself and patient. Just this experience has brought my son and myself closer and so I have to be thankful for that. Very fortunate to have the support that I have with my friends and family and a wonderful, supportive community. And I've made some beautiful friendships and lasting friendships are treasures. So, it hasn't been all bad and we always have to be optimistic and look at the good things.