

SHAPED BY ISOLATION

by *Natasha Lipman*

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For many people living with long-term health conditions and disability, isolation can become a strangely normal part of life. Whether you're bed-bound, house-bound, or pushing through and hiding your condition in public, there's a sense of loneliness that can become all-consuming. Many people may end up experiencing a significant drop in their amount of social contact, but there is also a sense of isolation that can come alongside living with conditions that are often misunderstood.

This article was commissioned months before any of us had heard of COVID-19, and the conversations around self-isolation and people feeling lonely, bored, and stuck at home have now become thrust, unceremoniously, into the front of public consciousness. Across chronic illness communities on social media, it's hard to avoid the frustration, often presented in meme form, at the quick adoption of strategies that will allow 'normal' life to continue remotely where possible. When it comes to work and school, the things that disabled people have been advocating for for years, especially in terms of remote work, seemed to be implemented in the blink of an eye.

Personally, I don't feel that all the conversations comparing this new reality to the chronically ill experience are particularly helpful — there's a difference between being healthy and staying home for a period of time that will end for many. But I also think that it's vitally important to remember that this new isolation does not exist in a vacuum. Millions of people have lost their jobs and are terrified for their lives or the lives of their loved ones. There are still so many on the front lines who aren't able to stay at home, and as such, I think it's not a stretch to say that the isolation mandated by this pandemic is in many ways not comparable to the isolation felt before.

It's within the context of this new normal that I've tried to write this article. It's not about isolation and coronavirus — and it's worth noting that the interviews are based on conversations had before the global relationship to isolation changed.

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Melissa and I have one of those 'friendship soulmate' relationships — knowing each other for only a week at a summer school back in 2006. We've barely spent more than a handful of weeks together since, but it never feels that way. In my mind, she always had one of those families that you'd see on a sitcom. They moved around so much growing up that their house became home to anyone that visited.

"I'm not 'from' anywhere and home is, as cheesy as it may sound, wherever I or my family are," Melissa explains. "I'm pretty good with change and can adapt quickly. Even the challenge of not knowing anyone is something that doesn't scare me that much — a lot of people who grew up moving around will agree as that was our reality most of our lives."

After graduating from university and starting a job in the film industry, Melissa woke up one day experiencing a pain she'd never felt before. "I had no idea that from that moment forward, everything about my life was going to change drastically. I had no idea the pain wouldn't go and that it meant I'd go from seeing friends a couple of times a week or month to once or twice a year."

Melissa was diagnosed with Trigeminal neuralgia, a chronic pain condition often described as the most excruciating pain on earth. She had to leave her burgeoning career, home, and friends in London to move back in with her parents who were living in a small town in southern Italy, suddenly finding herself in a long-distance relationship with her boyfriend.

"When everyone is telling you the more you rest the more your brain will 'heal', the more you'll recover, and the quicker you'll get back to being yourself again, it only makes sense to move to an isolated place, and I have immense privilege in being able to do so. But when you are physically isolated, and you realise the pain isn't likely to go away like you've been told, the isolation from having chronic pain feels that much heavier."

Melissa was experiencing two kinds of isolation — not only the isolation of staying inside because of her health, but the physical isolation of being miles away from the life she'd worked so hard to build. "That is the big difference between being physically isolated from your social life versus not being that far, I think. All you need some days is a conversation, or a meal together, or company whilst watching something because you're in too much pain for conversation."

For people who get sick when they're young, the experience is somewhat different, with isolation being a more normal part of their lives. Billie was diagnosed with ME/CFS when she was 15, after showing gradually worsening symptoms since she was 10. Billie missed a lot of school, but her teachers and doctors thought it would be best for her well-being to go back part-time so that she wouldn't become too isolated, doing the rest over the phone.

"I had always been the kid who was a bit different even before I got sick, and what my school and doctors didn't count on was that only going to school for two part-days a week just made me even more different. I was on the outside in a whole new way. I wasn't just missing out, I was being constantly reminded of all the things I was missing out on," she says.

"People forgot who I was and thought I'd left, other students would constantly tell me how lucky I was to stay at home all the time, even teachers didn't get the information they should have and assumed I was slacking off and never there. I felt left behind and forgotten, because I was."

Prior to her diagnosis, Billie had always been a high achiever and

volunteered her time across many aspects of the school. She decided to spread her final years out, eventually going to full-distance learning as she struggled to juggle both school and her health. So it was a big deal when she was invited to take part in a graduation ceremony at her school, even though she wasn't finishing with the other students her age.

Everyone received a school leavers certificate, a letter of recommendation, and a list of all the things they had contributed during their time at the school. "There was so much excitement in that moment, the anticipation of seeing it all laid out, the proof that I had been a part of this school, proof that I had made a difference and worked hard, even if I couldn't anymore. But the folder was empty," she says.

"I won't ever forget the feeling that followed, of being completely invisible — alone in a room full of people. They all carried on with their lives while I stayed in this emptiness, isolated and full of grief for the life that had been taken from me, a life that according to this folder and the people in this room, never even existed."

Billie spent most of the following two years at home. Her health declined, and she became mostly house-bound. To combat the loneliness, she spent time on a forum for people living with chronic illness, which helped her immensely. "Sometimes I felt like the isolation would swallow me whole. Sometimes days felt like a big squishy thing that I would sink into. I didn't feel like I belonged to anything."

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Now that our societal understanding of isolation has shifted so dramatically, Melissa can't help but wonder how things will change once this crisis is over. "Will [people] remember this experience and apply what they learned? Will they think about the company they longed for, the meal they wished they could go out for, the gig they wish they could attend? Being included, even if it's long-distance, still matters and can make a huge impact on our days, as everyone is now feeling."

Isolation is something that can teach us about who we are, the way we interact with ourselves and others, and the kind of society that we want to create. For many, this new reality of self-isolation, social distancing, and quarantine is just a pause in time that they can't wait to resume. But there have been, are, and always will be those who have been shaped by their isolation. And whilst I don't believe that this current experience is necessarily comparable to the chronically ill one, I hope it will fundamentally change what isolation means to people both inside and out of our community.