

MY SHIELDING EXPERIENCE

By Nadia

“So what’s your story?” he asked, sitting down next to me at a safe distance.

“I already told you my story. I was diagnosed when - ”

“No, not your cancer story. Your story. Interests, hobbies, passions, weird fetishes, etcetera.”

Like Hazel Grace Lancaster’s story in *The Fault in our stars*, my story is not an ‘arthritis’ story or just a generic ‘shielding’ story. When I talk about shielding to people, they often think this just means sitting at home, lying on the sofa and watching endless TV series to keep entertained. What needs to be understood is that as a person with a long-term condition and disability, shielding is an experience that we lived and practised long before the pandemic. We are masters in keeping ourselves not just entertained during shielding, but remaining an active and productive member of society, while still enjoying life. However, something about the pandemic changed our usual experience of shielding and that was fear. Fear of the unknown: a new and deadly virus that would be known as Covid-19.

Let’s start at the beginning with what was known as ‘the first wave’....

When I first heard about Coronavirus, my mind was focussed on trying to deal with even worse hyperemesis in my second pregnancy and trying to stay out of hospital. Coronavirus felt like SARS and Ebola; a virus in a faraway country that would probably never hit our shores. How wrong we all were to think this. I have one clear memory of going to a bustling Altrincham indoor market in March 2020 only to see if I could manage an outing without being overly sick and keeling over every half an hour. The seriousness of the virus had not yet come to light, but was about to hit us like a raging tsunami. I still feel incredibly grateful to not have caught the virus at this point especially in an indoor area brimming with unmasked people; the ideal breeding ground for Covid. I feel so lucky to have made it through my pregnancy safely, as I honestly do not know how my body would have handled Coronavirus at this time.

The week I was due to return to work following a three-month sick leave of constant hospital admissions and such severe morning sickness, we were in the depths of the first wave, which to me was more like an unstoppable tsunami. Nobody knew how to classify me. I spoke to my rheumatology specialist and my GP. The consensus was that I would not normally be advised to shield due to my autoimmune condition, seronegative arthritis, but my pregnancy put a question mark around the question of whether I should shield. I completed a risk assessment for my place of work in an NHS hospital. My manager concluded that I was ‘high risk’ and should only work from home. My rheumatologist specialist advised me to ‘stay home,’ but not officially shield at this point. I therefore worked my three working days at home and spent the remainder of the time struggling

to look after my two-year-old daughter with no outside family support, as we were not permitted to mix with anyone outside our household. My husband collected my medication from the pharmacy and did the food shopping. I remember food shopping being the most difficult task. At one point, I could only drink cans of Dr. Pepper and eat Walkers' Sensation crisps. He would patiently go from shop to shop to buy enough of a supply to meet my morning sickness needs. I later developed gestational diabetes, which made this even more arduous for him, as my diet became even more restrictive.

The only time I left our home was to attend medical appointments, which was met equally with excitement and trepidation. I remember the first time I saw clinical staff wearing full PPE at St. Mary's Hospital in Manchester. I had read about the use of PPE and redeployment in my employment contract and I clearly remember thinking that this would never happen. I could not have been more wrong yet I started wearing a mask as soon as we heard that there were Coronavirus cases in the UK and I made sure I kept my distance from other people. We even stopped our daughter going to nursery for a few months to minimise any potential contact with the virus. Something inside of us made us feel that we needed to be careful and I had to do everything to protect our unborn baby. I used to sit there in the waiting rooms at St. Mary's just staring at the staff wearing full PPE thinking how strange they looked; they were like characters from a sci-fi film. This sight no longer phases me, but just feels so normal.

I was put on a research project for work, but had no work laptop, as very few NHS staff worked from home. At first, I had little contact except for my department's WhatsApp group. Our Trust then set up WhatsApp and Facebook groups, which made me feel more connected to work.

Shielding during the first wave felt isolating, lonely and frightening despite having my husband and daughter with me. I used my work as a way to shift my focus from the fear of what would happen if we caught the virus. When I wasn't working, my focus moved to looking after and trying to entertain our two-year-old daughter who was equally anxious. She could not understand why she no longer went to nursery or saw any family or friends except on WhatsApp video calls. I over-used the English and French TV and our iPad to keep her entertained. We made caterpillars and other animals out of toilet rolls, made a sheep out of paper and cotton wool, and a home-made clock out of cardboard. We played with Play Doh, we drew and painted. We even bought a fold-up exercise bike that broke after two weeks, but she used to love sitting on it anyway and watching French cartoons. When the weather warmed up, we put her slide in her swimming pool and I would sit playing with her the whole afternoon. My husband also bought her activity tents to play in outdoors and indoors, which she still loves. While it was exhausting and I spent the whole time feeling ill, it was also great fun. My husband used to work abroad all week, but now we got to see each other every day and still do. There is no price that can be placed on family time.

I still used to look forward to the evenings when I had finished working and our daughter was sleeping, as I felt so exhausted. Every evening, I would stand and look outside our bedroom window. I would look at the windows in the houses opposite especially late in the evening when people would have their lights on. It was a reminder that there were still people out there. I would wonder what they were doing and if they and their families

were well or if they had been one of the unlucky ones to catch the virus. I would watch the sun set behind the trees. The last glow of sunlight for the day would feel so warming, so peaceful and relaxing, helping to retain a sense of normality and routine. However, it started to hit home when colleagues caught the virus and some of them passed away with it. What was most frightening was that some who lost their lives were fit, young and healthy individuals.

After I stopped working, I went out into our garden more and I started to go on short ten-minute walks in our street. The first time I set foot on our street, I remember feeling so afraid that Coronavirus was in the air outside and that I may catch it just by breathing the air and going on a walk. I would even cross the road to avoid people. What calmed me was the rainbow drawings and paintings displayed in our neighbours' houses. It was a fond reminder of work and the good we try to do in the NHS. I run a volunteers' service in a hospital and when I saw the rainbows, I thought about my volunteers and how they were. Some of my volunteers are painters and I imagined them creating beautiful rainbows and sunsets with gentle strokes of their paintbrushes. We had stopped our volunteers coming in to protect them and keep them safe, but I knew they would all be finding ways to keep busy and active at home.

I also took part in the NHS clap. It felt nice to acknowledge and thank my colleagues in some way, and also just to see my neighbours' faces. The clapping sound would echo down the whole street. It also made feel slightly useless, as I was not able to help my colleagues in the hospital and use my skills due to having to shield. It was an ambivalent feeling of needing to shield to protect me and my family, but not being where I felt I should be, using my skills and experience to help staff and patients in hospital.

As my pregnancy progressed with the double complication of managing diabetes and arthritis without additional family support, I had to finish work early. My GP also advised us to put our daughter back into nursery, which allowed me to rest more. Each medical appointment and stay in hospital just made me fearful. I had to experience my scans, appointments and hospital stays alone. Medical decisions I wanted to make with the support of my husband and parents, I had to make alone. I remember the antenatal diabetes' consultant one day telling me that I needed to be induced or have a caesarian section before my due date or I would risk my baby getting stuck or breaking bones during the delivery. I was so shocked and frightened. I had no idea what was the right decision to take. Thankfully, this decision was made for me. Our baby girl's cord was tied in a knot and I had to be induced, but ironically I had already gone into labour. I had to be induced alone on the ward and only my husband was allowed in the delivery suite. Following her birth, I was placed alone in a side room until I returned a negative Covid test. The woman in the side room next to me tested positive. It now felt that the virus was getting closer to home yet the atmosphere felt so much calmer than the birth of my first daughter. Our hospital beds were more spaced out meaning that there were fewer patients and the ward was quieter, so staff had more time to spend with us and support us. The staff were so calm and when they spoke of Coronavirus and 'Covid-positive' patients in the side rooms, it was as if it was normal.

Our second daughter was born just as we started to open up for the first time. Our family was able to see her and support us. I was still advised by my doctor to be careful because

of my health condition, but did not necessarily need to shield. At this point, I was classed as 'medium risk.' I would only see my mum and dad, and go on walks with a takeaway coffee in quiet, green areas in Cheshire. When I wasn't out walking, I was reading books from my bookcase, learning new recipes, finishing off painting projects, and watching English and French TV. I felt safe at home and in quieter outdoor spaces.

We hoped that we would stay safe, but then the Coronavirus wave hit us....

News broke of the AstraZeneca and Pfizer vaccines and as a family, we were all so relieved. We also felt very grateful to be living in a developed country with access to good healthcare and a Covid vaccine. Some of my family in Algeria haven't been so lucky. Some of our relatives have survived the virus, but others have not. This is the reality. My mum rushed to make my grandma's first dose appointment as soon as she received her appointment letter. We thought we would be the lucky ones who would manage to get the vaccine without catching the virus. We had come close a few times with me being in hospital near to Covid-positive patients and our eldest daughter had had to isolate due to contact with a positive case at nursery, but we had managed so far to evade the virus.

The day my grandma had her vaccine was cold, wet and dreary. Social distancing measures and mask-wearing were not being enforced at the clinic. She was crammed in a large queue of elderly people waiting to get their vaccines. At 89 years of age, she stood waiting for two hours to get her vaccine mostly outside in the rain with my mum. She was ill in bed for a few days following the clinic. We thought this was due to her being in the cold for so long. My mum looks after my grandma and had been helping to look after me and our new baby as I recovered from a difficult pregnancy as part of what was known as a 'support bubble.' What we hadn't realised was that my grandma was an asymptomatic carrier of the virus and quickly passed it to my mum and dad, then onto me, my husband and our two daughters. It felt so unfair. We had spent all that time trying to be careful and not mix with other family and friends, but only amongst ourselves as a 'support bubble.' We will never know for sure where we picked up the virus, but we think it is highly likely to have been at this vaccine clinic.

My mum had started to show symptoms late Christmas Eve. My husband was the first to really notice it. My mum is prone to chest infections, so we initially thought it was a chest infection. Two days later, I had just had my lunch when I suddenly felt really unwell and had to lie down. I started with symptoms straightaway, so we decided to book a PCR test. My mum, dad and grandma booked one on the same day, as my mum still was unwell, but not seriously ill at this point. My test was lost, but my mum, dad and grandma's tests all came back positive. My husband then did a test for him and our daughters, which were also positive. As soon as I had started with showing symptoms, I isolated in our bedroom and spent our second daughter's first New Year away from her. My husband would put her down for a sleep in her pram in the hallway. I would look down at her whenever I came out of the bathroom, but wouldn't dare go any further. It really hurt that I spent that first New Year away from her, my other daughter and husband when we actually all had the virus.

As a family, we had been concerned about how my dad and I would react to the virus, as he has a heart condition and is an ethnic minority, which were high risk factors at the time. Ironically, I was the only person in the family who has an autoimmune condition and whose oxygen levels were not affected, but the one person we did not think would become seriously ill was my mum who had no health issues. I remember my dad contacting me to say she had been admitted to hospital, but we hadn't realised just how serious her condition was until she told us her oxygen readings. I am still so grateful to my dad for panicking and pushing the paramedics to admit her. She was so unwell that the paramedics had to carry her from their bedroom to the ambulance outside. She was immediately put on oxygen, and given antivirals and antibiotics. The timing of her admission and access to this treatment saved her life. We have honestly all never felt so ill. What are described as mild symptoms of Coronavirus did not feel mild in any way. We struggled to look after our children. Our neighbours thankfully dropped off meals, food, baby milk, and activities for our children. It took us a few months to recover and even longer for my mum. Many people have asked if we are less afraid of the virus now that we have had it. I'm not sure that it makes you less fearful. There were shielding patients on the ward with my mum, which just evidences how easily transmissible the virus is. As soon as we could have our first dose of the vaccine, we booked our appointments straightaway. I am still afraid my twice weekly lateral flow tests will show two red lines instead of one despite having now had my booster and flu vaccines.

I received my second dose of the vaccine on the anniversary of the first lockdown, 23rd March when we were in the midst of 'the second wave.' I had always had some degree of hearing loss and an audiologist now advised me that my hearing loss had deteriorated to a level at which I required hearing aids. I had also just received a letter from the government advising me that I was now classed as 'clinically extremely vulnerable' and needed to 'shield.' I had to navigate getting used to wearing hearing aids and wearing them with a mask. I now had to think about shielding again. I wondered whether it was worth shielding now that I had had the virus and my two vaccine doses, but the thought of going through a similar traumatic experience again or passing the virus onto another person made me decide to follow government advice. We started to only have supermarket home deliveries and my husband would pick up the odd unavailable item in a local shop or supermarket. Our local pharmacy is very small, so I decided to continue picking up my prescriptions at quiet times of day. I still went on for short walks in remote, green areas and kept my distance well away from other people. I did not feel at the time that I could relive the trauma and anxiety of staying indoors for months. A better balance between staying at home and getting outdoor exercise in quiet locations felt a positive step for my mental health and road to recovery from Covid. I felt that I did very little during my maternity leave, but when I look back on this time, I was actually quite productive. I tidied up our home and did a big clear-out. I found the time to finish reading books I had started, try new recipes, finish painting projects, and enjoy time with my husband, daughters and parents. My husband and I even managed a short break to the Lake District with our daughters just before I returned to work in July 2021. It was honestly the best decision we made. We brought our own food, went on walks, breathing in and enjoying the country air and stunning scenery.

Shortly after I returned to work, I received my government letter advising me that shielding was coming to an end, but advice on how to move forward in this new Covid

world was unclear. Should I still be careful and go out at quieter times? Should I still wear a mask? In many ways, shielding felt like a warm secure blanket being wrapped in the safety of our home away from the virus. On the days that I work from home, I feel calmer and more relaxed. My husband is working in the next room and we have lunch together. At work, I enjoy speaking to my colleagues, but I'm still getting used to wearing a mask for most of the day and walking past the corridor leading to the ward filled with Covid patients, a place where my mum was once treated, but in a different hospital. It is still a challenge to hear and understand people wearing a mask and then to change masks without losing my hearing aids, but no-one ever said change was easy. I am glad to have some sense of normality and routine by being able to work some time in an office and at home although most of my working time is in the office, but I do ponder if we will live through another lockdown and whether shielding would be advised again. At least if shielding is recommended once more, we would have had some practice now and how to make the best out of this experience without being too fearful. Those 'shielding' and the 'clinically extremely vulnerable' are often viewed upon as fragile individuals who need protecting, but we are stronger than people think. We have had to live through many difficult times with our health and to develop strategies to manage our health conditions, while living our lives to the fullest. We are simply individuals who are more susceptible to contracting infections in general, not just Covid, and have learned to adapt and live our lives meaningfully and purposefully inside and outside our homes. Our story is much deeper and goes beyond diagnoses and health categorisations. We all feel, live and experience the wonders of our world even if it is differently for we are all human. Thank you for reading. Nadia.