

## **Living through Covid with an Immune deficiency**

I am 34 years old, married with two children (aged 6 and 2) and suffer with a rare condition called immune deficiency.

I was diagnosed at age 4 with Common Variable Immune Deficiency (CVID), after spending many years as a baby and young child being very unwell. It took quite some time to be given an actual diagnosis and I spent many years in hospital including intensive care, suffering with severe infections again and again.

Immune deficiency is an inherited condition where parts of the immune system are missing or not working properly. In my case, CVID means I do not produce protective antibodies which help to fight off infection.

Once a diagnosis of CVID was given I was put on lifelong medication called immunoglobulin replacement therapy to stay well and manage my condition. This requires you to have intravenous infusions, usually in hospital, or more regular subcutaneous infusions from home.

This life saving treatment allowed me to enjoy school, go to college, find my first job, and continue to work. I met my wonderful husband at work and we have enjoyed travelling, partying, and searching antique shops. Later we were blessed with two beautiful children.

Very early on we found out both children had inherited CVID. This came as quite a shock and wasn't something we had expected, we weren't aware my condition was genetic.

As parents, we got on with our lives, attending hospital appointments meaning we could be taught how to give our children their infusions at home to limit the amount of time they'd have to go to hospital and miss school etc. I guess the only saving grace to our situation was that we were familiar with the condition and I knew exactly what they were going through and experiencing. For this reason, we were the best people to guide them through. I'm so thankful for the immunoglobulin treatment that my children and receive, saying I'm grateful will never be enough, as this keeps us infection free most of the time.

In February 2020 everyone's world changed, but ours shattered. COVID 19 brought a whole new meaning of being alone / frightened into our lives.

With three extremely vulnerable people in the family it was a time I now look back on and still find myself in absolute shock this even occurred.

From March 2020 we literally locked ourselves away, friends were dropping things at our doorstep and food parcels from the government were being delivered as emergency items. We sanitised everything that came through our letterbox and front door and we kept our family safe.

In September 2020 our daughter was due to go back to school – at this time vaccinations weren't yet available and you can imagine this was a very scary time for us. My husband and I lost an awful lot of sleep from worrying about what to do for the best, daily / weekly.

In fact, when I look back now, that's exactly what we have done for 2 years - lost a lot of sleep, made decisions against GP's, schools' and some medical professional's advice because we felt our situation wasn't a one size fits all.

We were advised by one doctor to send our daughter to school in September 2021.

Our paediatric doctor agreed it was such a worrying time for us, and there wasn't enough evidence to support her going back to school with COVID whilst COVID 19 rates were still high, so we kept her at home and continued home schooling.

Thankfully that doctor understood our situation and treated us as an individual family whilst supporting us no end. Without him we'd have been made to send her to school and risk three / four people's lives prior to COVID 19 vaccinations.

The lack of support from professionals from here on out was very disappointing. I was forced to give up my job to home-school my daughter as I could not return to work. During this time the school gave us worksheets and a laptop and 1 hour lesson a week, online, with a teaching assistant. We had no choice but to hire a private tutor who could help us with home-schooling.

Having already done 5 months of home-schooling like everyone else during lockdown it was now harder as she was going into a different year at school and my 1 year old son needed my attention too as my husband was working from home to keep the three of us safe.

With the lack of help from school, I approached the council about some financial assistance with private tutoring as it was becoming difficult to manage.

They said they couldn't help as 'she didn't fit the criteria' but they couldn't tell me exactly what a child needed to be going through to get help.

It still amazes me now that this was the awful response we received. What does quality for help if being off school for medical reasons didn't fit the criteria? All they said was I was to speak to the school again. No support whatsoever.

After speaking to our school, they wanted my daughter to attend school (in a separate classroom) , but I explained her doctor had written to say 'she was not to attend school due to the global pandemic'. This was how we finally got the online lesson, once a week, from a teaching assistant. My daughter deserved so much more.

I took on the responsibility to home-school our daughter, with school providing some documentation to help. In all honesty I never felt supported and feel they let my daughter down immensely.

So much so, in 2021 we decided we would move her school as the lack of help became too much - we couldn't keep fighting in an already difficult situation, as no-one was prepared or able to help us.

Her new school have gone above and beyond to help us as a family including blended learning and putting certain risk assessments in place which allowed her to go to school part time with minimal risk to catching COVID and reassuring us as a family.

Thankfully once vaccinations were available, we felt better about life. However, another hurdle to climb was the fact that after two doses of the vaccine I was told I had made zero antibody response. After all this time (approx. 18 months of shielding) it meant I was no better off.

My husband continued working from home, my daughter was being taught at home part time so we could minimise risk and my son still couldn't attend nursery. We didn't socialise, go to parties, restaurants, supermarkets or even have any friends and family in our home this entire time. Meetings would be socially distanced, minimal amount of family members would come in our garden, we'd go on walks but that was our life.....for almost 2 years.

Once testing came into place, we would only see family and friends who were able to lateral flow test and put our mind at ease that they were not at risk of passing COVID onto us.

Just before Christmas 2021 the figures began to rise and we pulled our daughter out of school again and she remained learning at home full time.

As a mum I would get so upset about the upheaval in her life. The in-school, the out-of-school, seeing friends, changing school, not seeing friends, not going to parties. Not being a child. Why should my child miss out?

Christmas 2021, we cancelled plans, as Omicron was sweeping through the country and we were right back to March 2020 all over again. It was utterly devastating. I lost count how many times I cried and wondered how on earth I would go on.

But....you do. Everyday you'd get up and need to do it all over again. You would do it every day, for your children and family wouldn't you? We'd come this far - we had no choice but to keep going.

Medical professionals had let us down, some had been helpful, a school let us down, our council let us down but thankfully our daughter's latest school have been amazing.

Where I've really found comfort has been in talking to people on our community (UKPIPS Facebook page) for other immune deficient patients. Here, I have had more of my questions answered and worries calmed than anywhere else.

No one will ever understand the stress and anxiety Covid has caused me as individual; us as a family; and my husband and I as parents. The worry, the fear, and the torture of having to make big decisions feeling like you have no guidance, facts or professional help. Constantly swaying / backing up your decisions either way and just then in 2022 when you feel you just be getting a grip on life the Government decide to lift all restrictions and pretend COVID 19 no longer exists. I speak for everyone in my shoes when I say, 'We felt and still feel like collateral damage, forgotten and that we simply mean nothing'.

When the government decided to lift all restrictions, my world shattered again. I thought how could they be so irresponsible and treat vulnerable people this way? I'm a fair person and never expected the public to be shut away forever to help us but in March I was traumatised by the fact my daughter was going back to school and now children could be in school with no isolation or testing! How on earth was this fair to people like us? Do you know what this does to a parent's anxiety and worry?

The Government will never appreciate or understand that those decisions caused huge anger and upset to so many, because they didn't have to live through it like we did. Why were masks simply not just there to protect everyone still? Why can't people get tests? Surely people testing protects us vulnerable rather than just the vulnerable testing themselves. What's the point in that if normal people don't know if they have COVID or not and then come into contact with vulnerable people? Doesn't seem logical to me.

In March 2022, my daughter went back to school and a week later we all caught COVID-19. Our entire household tested positive the same time.

Our world was truly broken at this point, the constant fear of hospitalisation and being without my babies, or my babies being in hospital and I'd be on another ward. How would my husband manage?

Can you imagine the fear my husband felt, having a wife who is vulnerable and in hospital and two children who are also vulnerable and may end up in hospital with COVID 19? Do you think the government lifting all restrictions thought of families like us?

As soon as we all tested positive, I was a mum on a mission making sure we were all taking vitamin C, vitamin D and even some holistic approaches I'd been looking into in case this ever happened to us.

I had an oximeter at home, a thermometer at the ready, a nebuliser, paracetamol, Calpol ... making sure everyone was drinking water by the gallon and making chicken noodle soup a full of bone broth and nutrients.

In my mind if I could keep us all at home managing our symptoms, I'd won! We'd made it.

As I'm an adult I was so grateful to be offered the antiviral treatment. I'm forever grateful to our NHS and everyone involved in helping during this pandemic.

I mean I can't help but think had we have contracted COVID a year ago things may have been very different right now I'm grateful we got through COVID at home but the battle isn't over.



We have all been left with awful fatigue, constant cough and generally not 100%. I hope that this doesn't last, but who knows what the next few months will bring?

We are at risk of catching COVID again and again until we can get a prophylactic antibody treatment that would give us the same protection as anyone with a functioning immune system.

For now, I pray life becomes easier for us all and my children and us as a family can enjoy the life we deserve.

Leanne Preedy