

living with NEUROFIBROMATOSIS

This beautiful, yet heart-breaking letter has been written by an incredibly strong woman whose adult life has been at the mercy of this devastating genetic condition. Kirsty is a Mum to four gorgeous children, two of whom are battling life-threatening symptoms of NF.

Kirsty has chosen to share a different side to NF - the impact it can have on the entire family, not just those living with the condition. It speaks to the importance of self-care, of recognising when you may need help and a reminder that what you are doing right now, as a parent, is changing the life of the people most precious to you, your children.

Written by Kirsty Whitehead,
NF Mum



Part of advocating for your children means sharing their experiences to help others understand the sheer terror and trauma of a condition like Neurofibromatosis (NF), but knowing the reality is nothing you can prepare for.

My eldest daughter, Shelby is 16 and her brother, Jackson is 12. They both have NF1. I have been advocating for them for a long time, lending my strength and keeping my own emotional battles hidden - to relieve their anxiety and give them hope.

Lately I have been feeling the deep emotional

effects of their health challenges as years of bad news start to really weigh on me; too much for anyone to bear in silence.

Our journey has been a roller coaster. Sometimes I close my eyes and hold on terrified, waiting for the moment I can raise my arms again and simply enjoy the ride.

But after 16 years of tumours, surgeries, and a relentless stream of new health problems being diagnosed - each more terrifying than the last - you start to wonder how long you have left with your children. You start to reflect on what they will no doubt miss out on in life.

Will I be able to teach them to drive? Pick out a formal dress? Celebrate their graduation? Buy them their first legal drink? Or even watch them get their first job?



My heart sinks every time I watch Jackson push around a trolley while we shop, pretending he is driving a car.

Each time I remember that his vision impairment, intellectual disabilities, and other health issues will probably prevent him from ever getting behind the wheel.

There is so much joy in raising these beautiful children, but there is also so much heartache.

I'm actually a proud Mumma to four beautiful children. Joseph is 4 and Anna is 2, and they have lots of fun keeping me on my toes. Joseph and Anna do not have NF. Raising them has been an interesting journey and a great learning experience, but also quite painful.



Whilst I have loved watching my babies reach all their milestones, it has put into stark perspective the differences between them and their older siblings.

It is clear just how much Shelby and Jackson have struggled. Watching your four-year-old teach their 12-year-old brother how to do a puzzle is difficult to comprehend when you know it should be the other way around.

NF has affected every member of the family. Whilst my experience as a mum has been highlighted as a result of my campaigning, people often forget how it affects my husband, Shelby and Jackson's Dad and every child in the family.

The hospital has become the entire family's second home. Our two youngest children have never experienced a life where their siblings are not sick and don't require continual medical attention.

Inevitably, a day will come when they start asking questions. They will no longer accept this as their normal and want to know why their siblings have been dealt such an unlucky hand in life. They too will have to live with constant worry and anxiety.

Will another tumour grow? Will this be the tumour that takes their life? **These are questions that no child should have to grow up wondering.**

Not all cases are as severe as Jackson and Shelby's. In fact, doctors have said that many of their health problems only arise in 0.002% of NF patients.

We have been forced to face the uncertainty and mortality of our children, and this is when the guilt kicks in.

As a Mum you are fiercely protective and do everything in your power to fix things for your children. But what do you do when that is physically impossible?

I cannot take their pain away. I cannot cast a magic wand and make everything better. Instead, I hold my daughter as she sobs asking if this is the day she will die.

I watch my son curl up in a ball crying because he is unable to handle the pain. I have to answer them when they ask what they did so wrong to deserve this life, and listen to them talk about what colour they want their coffin to be.

Each time I must swallow the lump that is building in my throat. Because it is up to me to be strong.



If Mum is okay, it must mean everything will be okay. I have been pushing these emotions down so deep to avoid facing them, for so long that when they finally reappear, it is when you least expect it.

During these times, my husband becomes our emotional rock.

Our family faced one of the hardest moments of our lives just a few weeks ago.

Shelby required brain surgery to debulk a plexiform neurofibroma that had wrapped itself around the main drainage vein in her brain.

The surgery was life threatening. One small touch to this vein and Shelby would have a stroke or die on the table.

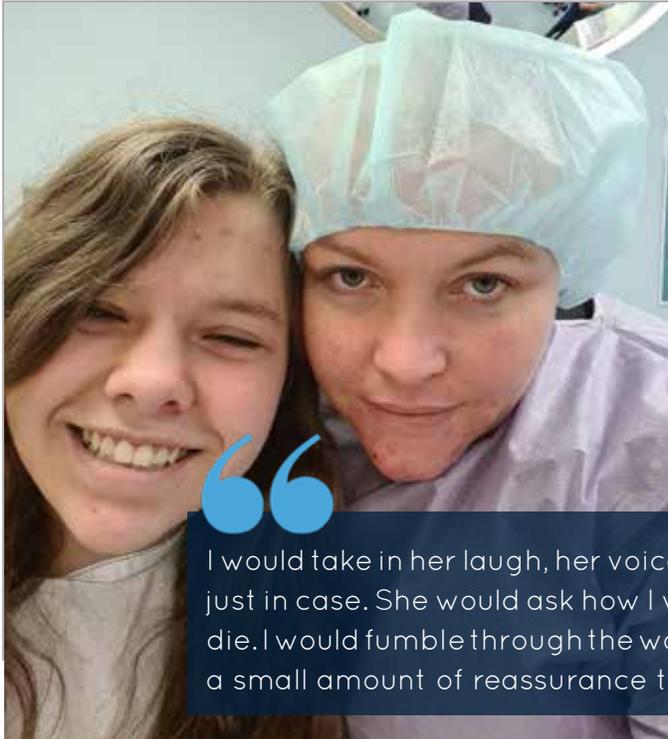
If we did nothing and let it grow, we would have the same outcome.

The sheer weight of the tumour was causing immense pain for Shelby and it became clear the surgery was necessary.

We were not prepared for how quickly the surgery would happen. We had only days to enjoy what could have been our last moments with Shelby.

I made it my mission to do things she loved every day; however, COVID-19 made it impossible to do everything we wanted. Instead, we enjoyed the small moments.

Going to the beach at night and dipping our toes in the cold wintery water under the stars.



I would take in her laugh, her voice and at times record it... just in case. She would ask how I was so sure she wouldn't die. I would fumble through the words and somehow bring a small amount of reassurance to her.

Shelby and I also talked about the experiences of other NF Heroes who were living with this devastating and unpredictable condition.

We talked about the impact that research could have on the lives of so many children with NF and knew the Children's Tumour Foundation (CTF) were seeking funding for an Australia-based MEK Inhibitor clinical trial.

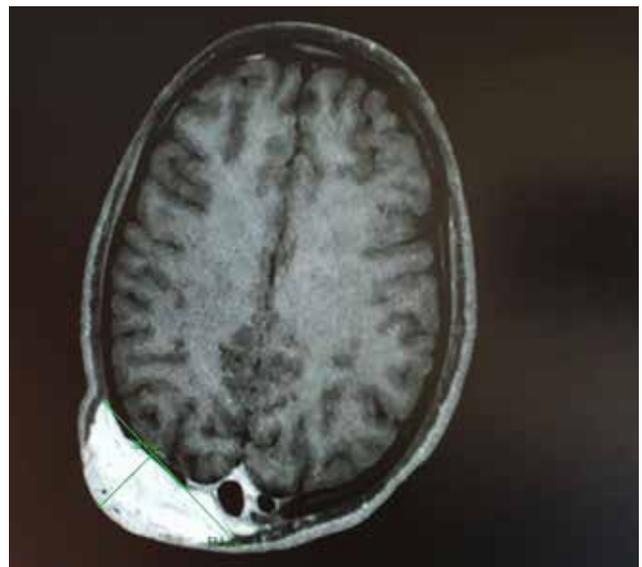
A drug with proven success in shrinking and stabilising the size of plexiform neurofibromas and optic pathway gliomas.

Together Shelby and I decided that it was our responsibility to help and by doing so, we could turn something negative into a positive. If the worst was to happen, the funds raised would be part of Shelby's legacy.

This became our family's focus in the lead up to her surgery and on Mother's Day I shaved my head. A small action in support of something so much bigger than me.

It became our focus to bring hope to other families and to ensure no child will have to face life threatening surgery simply to "buy them more time".

Thankfully, the surgery was a huge success. It went better than we could have hoped for. The debulking of the tumour went smoothly and they managed to do something we were told was impossible. They placed a titanium plate over the 5cm hole in Shelby's skull.



When you've been told nothing but bad news for over a decade, it is almost impossible to remain positive and hopeful.

Waiting for the news, I contemplated which 10 people we would have at Shelby's funeral. I wondered how I would break the news to her siblings, and how I would possibly cope with the loss of my eldest daughter.

I remember the moment the surgeon came and told me the good news. It has been years since we have received anything positive, so this was a lot to take in. It took me a little while to process just how amazing the news was. It felt like a little miracle.



While Shelby recovered at home, I finally had the opportunity to stop and reflect on who I am as an individual, the impact that NF has had on my life and how these experiences have shaped me. I have been a NF mum for over a decade, and this has consumed my identity. I have thrown myself into raising my children and making memories, knowing just how short and unpredictable life is.

“Through this process I have discovered a deep sense of grief - something I think I will always carry with me.

You see, I never imagined my life this way. I had goals, I had dreams. I wanted a career and, honestly, I wanted to change the world. That sounds kind of corny, but I always thought I was meant for something big.

I have struggled to figure out how to continue my goals as an individual, not just as a mother. These are feelings I have been unable to process on my own. So, I reached out to the Children's Tumour Foundation and made a connection with people who genuinely care. They have time to listen and it feels like they "get it" in a way most cannot.

During our most recent experience with Shelby's surgery, Ruth has been there through the tears, through my fears and through the subsequent grief I am now experiencing.

It was Ruth who really listened and helped me see that it is not that I'm not accomplishing my life's goals, it's simply that a world with Neurofibromatosis means my goals simply look different. That it is ok to feel, to be scared, but to also be hopeful.

I always thought the CTF was simply there to raise awareness for NF, fund research and find a cure. But, recently I learnt they are so much more.

There is a network to help families through the challenges this condition throws at us, and there is someone who will listen without judgement.

I wish I had realised this sooner.

All this time I have felt alone, exhausted and drained. Advocating for my children's needs would have been easier had I spoken to people with the resources and experience to help.