

Good morning. Thank you for this opportunity to share with you the story about our daughter Amy and what happened to her after receiving the Pfizer Covid vaccination in July and August of 2021.

My name is Sophie, I am Amy's mother. And I am here today with Amy's father Bruce.

So, you can put a face to the name, this is our beloved Amy.

She passed away suddenly and unexpectedly in her sleep, last year, on 2<sup>nd</sup> April, 2022. She was 24 ½ years of age. Her autopsy provided us with no cause of death and remains under investigation by the NSW Coroner.

Presenting to you today, is surreal. We are still coming to terms with the catastrophic and traumatic events which unfolded over 8 months, following Amy's vaccination. Today, 10 ½ months after her passing, the reality of living each day and forever without her, is overwhelmingly devastating and remains beyond our comprehension.

Our daughter Amy was an intelligent, gentle, kind, empathetic human. She was a loving and devoted daughter and big sister and best friend to her brother Hunter. Her family was the center of her universe and both she and Hunter, the center of ours. She viewed this world and the people in it, through a lens of beauty and kindness and found it difficult to reconcile, when it presented otherwise.

Amy was always highly risk adverse. A follower of rules. A passionate believer in equality and social justice, she felt a close affinity and personal responsibility to defend and protect those who were marginalized.

At the time of her death, Amy was one semester away from completing her Bachelor of Psychology degree at Macquarie University. This was posthumously awarded to her and presented to Bruce, Hunter, and I in October, last year.

As a child, Amy's coordination was not perfect, and she would tend to tire more easily doing physical activity. We periodically had her reviewed in her younger years, by her general practitioner and pediatrician, who could find nothing of concern.

She participated fully throughout her school years to the very best of her ability, she completed her Higher School Certificate, Bronze Duke of Edinburgh Award, a tour of Italy for her Ancient History studies, a student exchange trip to Japan and a trip to an orphanage in Cambodia volunteering teaching English.

In 2019 and 2020, having graduated from high school, Amy noticed that her coordination and fatigue were slowly worsening. Over a 12-month period, we saw many specialists – rheumatologist, cardiologist, eye specialist and neurologist, to try and find the cause of these issues. Despite a myriad of tests, no one could find anything of grave concern or form a diagnosis. They would only reassure us, that whatever "it" was, was progressing very slowly and would just need to be monitored. In the meantime, Amy commenced weekly physiotherapy. This worked well. Amy achieved good results and felt stronger.

We were then referred onto a Neurological Geneticist at \_\_\_\_\_, to see whether they could identify a genetic cause of Amy's issues. Many, many vials of blood were taken and yet no genetic condition could be identified. We were told they had exhausted all genetic conditions they could think to test her for and recommended six monthly appointments to monitor.

The Neurological Geneticist did diagnose Amy with Clinical Hereditary Spastic Paraplegia – a degenerative disorder that involves weakness and stiffness of the legs. Amy had tested negative for this condition genetically, but it was the closest condition to describe how Amy presented clinically – and would allow Amy to apply for NDIS funding, to cover costs of ongoing physiotherapy sessions and help at home, should she need it.

Her life in June 2021, at the age of 23, just prior to receiving her COVID vaccination, was wonderful. She was living independently in her own unit, which she had proudly furnished and decorated and loved. It was close to where her dad, brother and I were living, and we would all see each other regularly. She had her drivers license and owned her own car. She was enjoying full time studies at Macquarie University. The month prior to this, she had been chosen to walk in her favourite artist's catwalk show, meeting a group of inspiring, diverse women, all of whom had overcome significant challenges in their life.

Meanwhile, COVID had arrived on our shores. The long-awaited vaccinations had started to be rolled out. We, like many Australians, had watched the COVID pandemic and rates of illness and death, sweep across the world. We were so fearful. Life as we knew it and the freedoms we enjoyed were fast disappearing. Due to Amy's clinical hereditary spastic paraplegia diagnosis, she was classified as 1B for the purpose of getting vaccinated. Second in line to receiving the vaccine, after the elderly. The narrative at that time, was loud and clear – 1B – most at risk of developing serious illness and/or death from COVID. Understandably, Amy was very concerned for her own health, but was also concerned for the health of her family, her friends, and vulnerable people in the community. She morally felt a strong sense of responsibility, to play her part, get vaccinated and protect herself and other people. We as a family, were intently listening and following the daily advice of government.

In June of 2021, on two occasions, we sought the advice of Amy's General Practitioner to discuss Amy's COVID vaccination. Amy had been a patient of this practice for over a decade. Her GP said she would not discuss Amy's vaccination with us, that we must discuss it with Amy's current treating specialist, which at that time, was the Neurological Geneticist at .

We made that appointment and as directed, on a teleconference call, we sought vaccination advice from the Neurological Geneticist. We were told that as category 1B, Amy must be vaccinated with Pfizer, as a matter of urgency and to book into the Vaccination Centre as soon as possible. We followed this advice, securing appointments on 16th July and 16<sup>th</sup> August 2021 for Amy to receive the recommended two shots of the Pfizer vaccine. We were so relieved.

I was present on that teleconference call with Amy and the Neurological Geneticist. There was no discussion of whether it was safe for Amy to be vaccinated, what (if any) were the risks, which vaccine was most suitable, what (if any) side effects to be aware of, whether she – a Neurological Geneticist, was best placed to assess Amy's suitability to being safely vaccinated. There was no offer of medical supervision or monitoring of Amy either during or after her vaccine. Nothing. Just get vaccinated and I'll see you again in 6 months.

We felt safe and assured, following and trusting both government and medical advice. At that time, it did not occur to Amy (or Bruce and I) – that perhaps Amy being classified 1B– also put her at the greatest risk of having an adverse reaction or dying from the vaccine.

On the 16<sup>th</sup> July, Amy attended the Vaccination Hub at and received her first dose of the Pfizer vaccine.

In the coming days, Amy would tell us that she was experiencing some pain in the arches of her feet. She had experienced this pain a few years prior, and orthotics and foot exercises had alleviated it. Thinking nothing of it, Amy recommenced those foot exercises and we made an appointment with a podiatrist to get some new orthotics.

Over the coming weeks, Amy would notice gradually, mild numbness in her feet, some slight deterioration in her balance and coordination – which we mistakenly thought was all related to the pain in the arches of her feet.

On 16<sup>th</sup> August, 2021, 4 weeks after her first vaccination, Amy attended the Vaccination Hub at [redacted] and received her second dose of Pfizer. Over the coming days, Amy experienced aches in her legs and arms. The numbness in her feet worsened and began spreading up her lower legs to her shins. Her heart rate became elevated, she felt breathless at times and her balance and mobility worsened. She noticed perspiration on her back.

On 22<sup>nd</sup> August, 2021, 6 days after receiving her 2<sup>nd</sup> vaccination and with Sydney in COVID lockdown, we emailed Amy's treating specialist – the Neurological Geneticist, requesting an urgent appointment and listing the timeline of Amy's post vaccination symptoms. We secured an appointment two days later. By this time, Amy was finding it difficult to stand and walk. An urgent nerve study, lumbar puncture and MRI were ordered. The results showed little to no change from these same tests Amy had had, 1 year earlier.

Based on these findings of these tests, the Neurological Geneticist would conclude that Amy's symptoms and rapid deterioration were not vaccine related. The circumstantial evidence of Amy's rapid deterioration post vaccination told us otherwise. When we questioned this conclusion, we were firmly told we needed to "let the vaccine theory go".

Our distress increased daily, as Amy's condition continued to deteriorate. Our attempts to call and email her treating specialist were largely ignored. On 6<sup>th</sup> September, Bruce and I would receive an email from her, advising that as Amy's treating doctor, she would no longer have any direct communication with either Bruce or I. She advised that this was normal medico-legal practice to communicate only with her patient, Amy, as she was over 18 years of age. We offered to get written consent from Amy for communication with us, of which she gave no response.

The distress this caused was immeasurable. We were made to feel as though we had done something wrong, we were unreasonable, irrational, perhaps even offensive, to suspect our daughter's sudden and rapid deterioration had been caused by the Pfizer vaccine.

We felt outcast, helpless, sick with worry. We didn't know what to do or where to turn. Amy was diagnosed with severe anxiety and panic attacks. She was terrified and overwhelmed at having to manage decisions about her medical care on her own. There was no plan of treatment from the treating specialist, nothing.

We knew this was not right. As Amy continued to deteriorate, we knew something was seriously wrong.

In desperation, we reached out to Amy's Neurologist, who had referred us onto the Neurological Geneticist. He agreed to see us as a matter of urgency on 7<sup>th</sup> September, 2021 – less than a month after Amy had received the second dose of the Pfizer vaccine. Within minutes of reviewing Amy, he diagnosed her with post vaccination neuritis and recommended her immediate admission into hospital to receive immunoglobulin (IVIG intravenously) for 3 days. We were assured that Amy was

going to be OK, she just needed this treatment to reverse the effects of the vaccine and she would recover in 1 to 4 weeks time.

Too unwell to continue her university studies, Amy deferred her degree on medical grounds.

She was admitted into \_\_\_\_\_ on 9-11<sup>th</sup> September. This was a distressing time for her. On top of her health rapidly deteriorating, she had a severe needle phobia. Her veins difficult to find and prone to collapsing. The hospital was in lockdown, no visitors. We applied for an exemption on mental health grounds and thankfully we were granted permission for one parent to visit.

After Amy was discharged from hospital and over the next couple of weeks, we would not see the promised improvements. In fact, Amy continued to deteriorate. The numbness in her lower legs had now spread to her hands.

She was reviewed again by her Neurologist and it was recommended she return to hospital for another round of immunoglobulin treatment with the addition of steroids. Another distressing hospital admission.

We asked Amy's Neurologist how he knew it definitely was the vaccine causing this and he replied, "because there is no known neurological condition that could cause such rapid deterioration in such a short period of time". Once again, we were assured that with this treatment and time, Amy would make a full recovery.

With Amy's balance and coordination continuing to deteriorate and the numbness in her lower limbs and hands, Amy was prescribed a walker to mobilise safely. Her voice became frail and high pitched. She would begin weekly sessions with a psychologist to manage the trauma, anxiety, and panic attacks she was experiencing.

She retreated from her friends, not wanting to disclose what was happening to her after being vaccinated. She feared being seen as "anti-vax" and did not want to deter her friends from being vaccinated. Despite what was happening to her, she wanted to protect her friends and their families from Covid.

Two weeks later, on 13<sup>th</sup> October 2021 and 2 months after her second Pfizer shot, Amy was once again reviewed by her Neurologist. She was extremely weak and fatigued. She was now requiring the use of a wheelchair.

Her Neurologist would recommend rest and physiotherapy at home to regain strength and mobility. A couple of weeks later, Amy would dislocate a knee at home during a physiotherapy session, and further sessions were put on hold.

Throughout November 2021, Amy needed assistance at home with all personal care, including showering and toileting, and to mobilise safely. With full time jobs and having exhausted all our leave, Bruce and I, juggled our work commitments and caring for Amy around the clock, hopeful that in time, we would see the promised recovery and improvements in her strength and mobility.

Mid November 2021, Amy was reviewed again by her Neurologist and it was then recommended she be admitted to an in-patient rehabilitation center for 2-4 weeks for intensive rehabilitation and nursing care. We were referred to and reviewed by \_\_\_\_\_ and as they were full, we were placed on a waitlist. Amy was admitted two weeks later on 2<sup>nd</sup> December 2021.

On admission to rehab, Amy was unable to stand, walk, write, shower, toilet, or cut up her food on her own. She needed to be hoisted for transferring from her bed to a wheelchair. Her vision had also deteriorated, she was unable to read books or watch television.

Amy would remain in \_\_\_\_\_ for 2 months. This time was extremely traumatic. Devastatingly traumatic.

From the day of Amy's arrival at \_\_\_\_\_, our expectation of a 2-4 week stay and promised recovery of strength and mobility, were not shared by her treating team. Amy would ask them daily "how long am I hear for" and "will I ever walk again" and they would all say that they could not answer those questions.

During this time, the rehabilitation centre was in Covid lockdown – no visitors. Once again, Bruce and I applied for an exemption based on mental health grounds, and thankfully this was granted. Our visits with Amy, were greatly distressing. She was distraught.

She would ask her dad and I questions that we struggled to answer. Why wasn't she getting better, as her Neurologist kept promising? When could she come home? Was she ever going to walk again? We did our best to reassure her, trusting what the Neurologist had said and the treatment she was receiving.

As her mental health deteriorated, she would eat less and less and began rapidly losing weight. I noticed her beautiful thick mane of hair was falling out too.

At the end of January 2022, the doctor leading Amy's treatment at \_\_\_\_\_ met with Amy, Bruce and I to let us know, that after two months of treatment, they had decided, it would be in Amy's best interests to be discharged and continue her rehabilitation journey at home. Her mental health was deteriorating, and her physical recovery was slow and inconsistent, which they attributed to her anxiety. Every day, Amy would say to me, "I'm sorry Mum, I really am doing the very best I can". She was made to feel that it was her fault, that she wasn't improving fast enough.

In the coming days, they would focus on teaching Amy how to independently transfer in and out of a wheelchair – but she was going to need ongoing intensive outpatient rehabilitation and carers at home to help her with all tasks of daily living. Whilst Amy was devastated to be leaving in a wheelchair, she was so relieved to be returning home.

The doctor recommended that we contact Amy's case manager at NDIS to have her existing funding reviewed and increased, due to Amy's change of circumstances and this would assist us with the cost of Amy's ongoing treatment and care.

We submitted an urgent application for review with NDIS, with supporting medical documentation. We were shocked to hear back from them within days, that because Amy's change of circumstances was vaccine related, her treatment and care was the responsibility of Department of Health – not NDIS – and if wanted to proceed with the review, they threatened to immediately cut off Amy's existing NDIS funding. As we needed this funding for Amy to return home and cover the associated costs, we withdrew the request for a review and planned to revisit once we had Amy home.

We were very overwhelmed. We had to self-educate about home care – the companies, online platforms that offered this assistance. We interviewed many carers and thankfully, found three wonderful ladies – a practicing nurse, a retired nurse, and an occupational therapy student – who would help us with the daily care of Amy. We contacted the rehabilitation center that Amy was doing physiotherapy with, prior to her vaccine and they designed an intensive outpatient

rehabilitation program, in-house and home based. We made some modifications at Amy's unit, purchased needed equipment and at the end of January 2022, Amy came home.

Team work would make the dream work.

Amy's beautiful carers, her psychologist, her rehabilitation team, her devoted family and at the center of it all, our strong, brave, resilient daughter – who each and every day, got up and fought with such strength and determination, to get back to her independent life.

Over the coming months it finally started to pay off. Amy made slow and steady gains in her recovery. The numbness and sensory nerve issues had subsided. But there were residual issues with her motor nerves and proprioception.

On 2<sup>nd</sup> March 2022, Amy was reviewed and had a comprehensive physical assessment by her treating Neurologist – 6 ½ months after her 2<sup>nd</sup> Pfizer vaccination. Despite Amy still being unable to independently stand and confined to a wheelchair, he would write that Amy's examination had improved remarkably and once again, we were reassured, she would fully recover and walk again. We just needed to keep going with her rehabilitation.

We all wept with relief.

One month later, on April 1<sup>st</sup>, 2022, what none of us knew, this day would be Amy's last day on Earth. There were no warning signs, that her death was imminent.

Amy was mentally and physically the strongest she had been in months. She had a positive session with her psychologist – she was in good spirits with the progress she was making – there was still a very long road ahead. Also, that day, in her physiotherapy session, she had walked aided, 22 meters – the furthest she had walked in months.

Her dad and I both had Covid that week and were in isolation. We spoke with her daily on the phone and via facetime, as she proudly shared her successes or vented her frustrations – but we missed out on spending with her, her last few days.

That night, on the Friday, 1<sup>st</sup> April, she ate her dinner and with her carer's help, she went to bed. She watched her favourite musical on her phone, Phantom of the Opera, sent her usual "goodnight" and "I love you" texts to her family, tucked her phone under her pillow – as she always did, and went to sleep.

The next morning, Saturday, 2<sup>nd</sup> April, 2022, her carer arrived to help Amy with her morning routine. She found Amy, neatly tucked into her bed. She was cold and unresponsive. She had peacefully passed away in her sleep. Her carer called an ambulance. The ambulance came. There was nothing they could do.

I received a call from the carer's agency, asking me to urgently call the carer's phone who had found Amy. I called and the phone was answered by the ambulance officer who told me "I am very sorry to tell you that your daughter has passed away".

We were, and are, in complete shock and disbelief. How could this happen?

Conversations in the coming days with family, police, the coroner's office, the funeral home. Organizing our daughter's funeral. The cremation. The scattering of Amy's ashes. It is all a blur, yet traumatically vivid at the same time.

The autopsy has offered no insight into why Amy died; it did show significant damage to nerves in her spine – far greater than we expected. She was never going to make a full recovery. How did the doctors and their tests get that so wrong? It is beyond belief, given the state of the damage in her spine, she was managing to stand and walk at all in those last few months.

Today, we welcome the coroner's ongoing investigations into Amy's death, and we welcome the opportunity of sharing our submission to this parliamentary inquiry. We have many questions that remain unanswered.

Given Amy had an unknown underlying neurological condition, it is hard to know with medical certainty, whether Amy's drastic deterioration in her health post vaccination and sudden, unexplained death, was due to her underlying condition and/or the Pfizer vaccine.

We don't know.

But, what we do know with certainty, is the circumstantial evidence. Our beautiful, healthy, happy, 24-year-old daughter, fell off a cliff after receiving her Pfizer vaccinations. We went from 6 monthly monitoring of a slowly progressing underlying condition, to 8 months of horrific physical, mental, and emotional suffering and a sudden, unexplained death.

Her life was taken from her at 24 ½ years of age. Her love, her kindness, her laughter, her friendship, her dreams of travelling the world, a career as a school counsellor, a family of her own – was all taken from her and taken from us.

As a parent, we have been dealt the worst card. We have seen others endure the loss of a child. We have always feared it. And here we are. It is now ours to endure.

I know that Amy would be here today, living her wonderful life, but for receiving that Pfizer Covid vaccine.

More consideration by the medical profession should have been given to whether it was safe for Amy to be vaccinated. More consideration should have been given to which (if any) vaccine was safe for her to receive. Amy should have been closely monitored on receiving the vaccine – so those early signs of an adverse reaction, could have been identified, treated and a second dose stopped. Our initial concerns that Amy's symptoms were vaccine related, should not have been so readily and defensively rejected.

We reported on the government website that Amy had an adverse reaction – we have heard nothing. In our opinion, all aspects of that government vaccine portal, is grossly inadequate.

Australians who followed the health advice and got vaccinated against Covid, and experienced either an adverse reaction or the loss of a loved one, must be given the opportunity to share their stories. They must be better supported and compensated.

Lessons must be learnt. There must be accurate reporting of adverse reactions and deaths – so that further research is done on the Covid vaccines. Medical practitioners should be better educated on the safety of vaccination, side effects and treatment – so that in future, we may all be better equipped to give our informed consent on whether or not to be vaccinated. Particularly critical for those amongst us who are most vulnerable.

We hope this is the first of many Covid related parliamentary inquiries. We would welcome a royal commission into the handling of the Covid vaccination roll out. Perhaps being here today and sharing our story with you, is a step in the right direction. We will never recover from what has

happened to Amy and our family. Please help us to ensure that it never happens in this country again.