



# NEURODIVERSITY AND BABY LOSS MINI SERIES

WILLOW'S RAINBOW BOX



Willow's Rainbow Box is a charity that supports families through pregnancy after loss. Our aim is to promote positive mental health and wellbeing in pregnancy after loss.

As part of the work we do, we also acknowledge the importance of the journey through loss and its impact on subsequent pregnancy. We believe it's important to provide opportunities for people from diverse communities to share their voices and experiences and this is why we create these spaces.

We have created a baby loss series for South Asian communities, a Black baby loss series, an LGBTQ+ series and now we have our neurodiversity baby loss series. The stories shared are from people from across the world.

These stories are people's real, lived experiences. Please take care when reading these stories and respect the voices and experiences shared.



### Kiley's story:

Kiley is the founder of Return to Zero: Hope. Kiley was diagnosed with ADHD and Autism late in life and didn't know at the time of her stillbirth.

'For those who know me, I appear stoic and don't usually express emotions outwardly (which I can now attribute to alexithymia). My internal experience, however, is completely different, as I am highly empathetic and feel deeply. I became curious to understand how my response to my stillbirth could be viewed through an autism lens. From the time that I found out Norbert's heart had stopped beating and through the birthing process, I became suddenly overwhelmed and unable to process anything. This sensory processing failure led to shutdown. I was in shock, numb and disassociated. I did not cry. I also judged myself because I did not grieve in the 'expected' way.



It's important for us to understand that the appearance and needs of Autistic people differ from the typical grieving person. In a split second, I experienced the loss of my assumptive world. I needed facts, information, a plan, guidance (from providers), which I did not receive. With this tremendous uncertainty, my fear and anxiety skyrocketed. With Return to Zero: HOPE I created what was missing in my own life experiences surrounding the stillbirth of my son in order to help other people navigating this experience.



## Victoria's story:

Victoria is a doula and is neurodivergent. She tells her story of baby loss on her blog.

In August this year I spent an amazing month back home in Scotland visiting family we had not seen for over a year. It was blissful. Thanks to all the help from very enthusiastic grandparents, I felt physically better and more rested than I had in a long time. But during those weeks I experienced some very strange bleeding after my period. Sometimes it was pink or brown and watery, other days I had a full bleed more like a period (although I wasn't due for some time), and then within a day it would abruptly stop again. The thought of pregnancy didn't cross my mind once. We were taking precautions, and I'd had what I thought was a normal period after the last time we'd had sex. So it just wasn't biologically possible as far as I was concerned.



I was worried about why the bleeding was happening and so I booked to see a gynaecologist on my return to Paris. The gynaecologist performed an internal ultrasound and commented that the wall of my uterus was thicker than it should be, and although she couldn't see a pregnancy on the scan, she advised that I take a test. I actually laughed out loud; to me it was just not possible.

She said that the next step would be to do some diagnostic tests but the first box to tick was the home pregnancy test, so of course I did as she asked. Three positive tests later, I sat in shock in my bathroom and emailed her. I could not believe it, and felt such a mix of emotions. Confusion, fear, and some excitement. But I had a niggling doubt that this was a viable pregnancy. I had never bled during either of my previous 2 pregnancies. And the dates just didn't make sense.



Within a few hours of the appointment I began to bleed again, having not done so for about a week. It felt odd. Was I now feeling some relief? But definitely sadness too. Could it still actually happen? How the hell were we going to manage with 3 small children in a flat in Paris with no family support? We were already struggling. I spent the evening imagining elaborate details about morning routines and bus routes so that we could get our girls to school and nursery, but with a baby in tow. And then I'd go to the toilet and see blood again...

The gynaecologist emailed me a prescription to have a blood test to confirm the pregnancy and advised that it be repeated every 48 hours to monitor what was happening to the hCG levels. The test confirmed pregnancy but the levels dropped within the 48 hours, although not by as much as would be expected if I was miscarrying.



I had now passed a lot of blood and some tissue. I was asked to go back to the hospital for a scan, as there was concern that this could be an ectopic pregnancy. It was a difficult time for me in that waiting room. I was in the prenatal scanning clinic, surrounded by what felt to me like happy couples, who were waiting to see their babies for the first time. I knew my pregnancy was coming to an end. The question was whether or not there was any danger to my own health at this point. My mum had had an ectopic pregnancy and a Fallopian tube removed before I was born. I was terrified of surgery and the recovery that would follow. I was alone and scared. The sonographer couldn't locate the pregnancy on the scan or any signs of where it had been, but she seemed optimistic that it may just be a 'straightforward' miscarriage. I was sent home again. The Gynaecologist still could not see anything on the ultrasound, she explained that she had no choice but to diagnose an ectopic pregnancy.





She described the risks to my health of the pregnancy rupturing, and prescribed a medication called methotrexate. To my shock, she then proceeded to tell me that the hospital did not have any of the medication on site, and that I would have to go to a pharmacy myself to collect it, and also find my own nurse to administer it. This is not uncommon protocol in France. But it certainly added to my stress and anxiety at an already very difficult time. It was 4pm, and she told me that I needed to have the injection today, but only after I had the results of a liver function blood test amongst others. Somehow I needed to head to a laboratory for the tests, get the results, source the drug, and find a nurse who would come to my flat in the evening to inject it. All whilst picking up my daughters from childcare and getting the dinner on. It didn't seem possible, and I felt numb. Why was I being tasked with all the logistics of my care when I was reeling with the news of what was happening to my pregnancy?



Luckily my husband Chris had been working from home that day, so while I was at the lab having the suite of tests done, he went to our local pharmacy who helped him to find a nurse and who found another pharmacy across town with the medication in stock. We arranged to have it taxied over to our pharmacy. However the results of the lab tests needed to be reviewed by my doctor before I could have the injection, and by 10pm I still hadn't heard anything. It was a stressful evening of waiting and a pretty sleepless night. The results were in early the next morning, and I had the green light to get the medication. I managed to persuade the nurse to squeeze me in asap, but on arrival he realised that the pharmacy had sent the wrong type of drug. We were back to square one. I'm very grateful to him as he was the first person who showed me genuine compassion about the situation. He offered to sort it out with the pharmacy himself, and to text me when he had the right medication. This took all day, and at 6pm I finally had the injection.



The next few days were spent mainly on the sofa watching trashy tv, and trying to process what had happened. I was struggling to be present with the kids and continue with all the things I needed to do, so I reached out to my Dad for help and he flew over from Scotland the next day. This was a huge relief. The kids were excited to have him here, and it meant that I didn't have to worry about school runs, pick-ups and lots more. I was also worried that things might ultimately result in me needing surgery, so having him already on hand should that happen, was a huge comfort.

Over the next couple of weeks the blood tests showed that my hCG levels were now rapidly going down, and I no longer needed 48 hour monitoring, but would need a blood test once a week until I had a negative pregnancy test. I cried a fair bit during this time. I had noticed some pregnancy symptoms including a bit of crusty colostrum on my nipple one morning in the shower.



These were now disappearing, and I was watching my pregnancy slowly unravel with each blood test. I wanted it to be over and to get the negative test, but at the same time, I felt a connection to the beginning of life that we had made. I was saddened by some of the language that was used by others in conversations I had. One friend said 'it was a blessing' because we hadn't planned for any more children. A nurse at the laboratory who took my blood said the main thing was that I already had children. Their opinions were not asked for, and were painful to receive because they didn't validate how I was feeling. Unfortunately, the day after my Dad left, Chris, my eldest daughter and I were in a taxi when I suddenly started to feel a lot of pain low down in my abdomen. I questioned myself as to whether or not it was in my head, or if it was something digestion-related, but by the time we got to our destination, I was in tears.



I repeated over and over 'I'm sure it's nothing', but really I felt that something was very wrong and I needed to get to the hospital. So we got straight into another taxi and headed there. On arrival I was asked to give a urine sample and I noticed that I had started bleeding vaginally again which confirmed to me that my pain was related to the ectopic. They quickly hooked me up to some intravenous pain relief which helped but I was still in a lot of discomfort. Chris took my daughter home to sort out childcare for both our girls and planned to come straight back. This time spent alone was very frightening. My body started to show symptoms of shock. I suddenly found that I couldn't move my arms or legs, and my hands and fingers became completely frozen in the position I had been holding them. I felt tingling and pins and needles spread up my whole body. I shouted for the nurses to help me. They appeared confused as to what was going on. They spoke a little English but not a great deal, and my lack of French vocabulary didn't help with the confusion.



I started to panic. It was one of the most frightening experiences I have ever had. They gave me some more medication to relax my muscles and luckily this helped and I started to drift in and out of sleep. I was then wheeled back to the prenatal scanning clinic. I must have looked quite a sight to the couples in the waiting room; sat in a wheelchair in just a hospital gown and socks, drifting in and out of sleep. I was surprised that they left me alone in the corridor outside the scan room until the sonographer came to collect me. During the scan she still couldn't locate any sign of a pregnancy, but she could see that I was bleeding into my abdomen. A few hurried phone calls were made in French which I struggled to understand. I was wheeled back to A&E to await the arrival of my doctor (who had been called in from home) and be prepped for her to perform keyhole surgery.



I was told that they needed to find the pregnancy and stop the bleeding, and that if possible, they would remove just the pregnancy, but there was a high chance that they may also need to remove my Fallopian tube.

Everything happened fairly quickly. I remember the theatre nurses being very jovial and playing around. One of the nurses threw a plastic sheet at the other one and they pretended to have an argument. It felt surreal. This lively mood didn't match how I was feeling. I was disoriented because I had to leave my glasses with Chris and I couldn't see much. I just wanted the sleepy feeling of the anaesthetic and for this to all be over. I felt triggered from my difficult postnatal experience with my first daughter, which ended up with two separate trips to theatre.

I came round on the recovery ward and drifted in and out of sleep. I was eventually taken to my own room, where Chris was waiting.



He told me that the doctor hadn't been able to save my left Fallopian tube and that it had been removed. I wasn't surprised. I had felt a quiet acceptance before going into theatre that this would be the outcome. We chatted for a bit but it was now late and he needed to go home to get back to the kids. He told me that my mum was going to fly out the next day to help us out.

I spent 2 nights in hospital. I was very grateful to have my own room after my experiences of the understaffed and very busy postnatal wards back home in Scotland. I made sure I pushed my buzzer as much as I needed to get help with going to the loo etc. After I had my first daughter, I frequently pressed the buzzer and had no response. I made a promise to myself I wouldn't struggle alone this time.





Thanks to the amazing support I received from family and friends, I was able to treat the following weeks like a different type of postpartum. I talk to clients about the importance of physical recovery, nourishing foods and social support after having a baby. The same principles apply after loss. I slept, and spent a lot of time on the sofa watching tv. I ordered some amazing nourishing food that only required me to press a few buttons on a microwave. I spoke to a therapist, and was doula'ed by my amazing doula mentor Lisa. My mum and Chris took care of the household stuff and the kids' needs. I am now emerging from this bubble of recovery. I'm getting out a bit more and meeting up with friends. I'm laughing again, and enjoying time with my children. I'm sad about what has happened, but I feel ready to make plans again, and I'm excited about things to come in the future.



I think having an ectopic pregnancy can be one of the most complicated emotional experiences someone can have. I have felt an overwhelming mix of emotions, including confusion, excitement, grief, and genuine fear of death, but also relief and gratitude. All alongside the rollercoaster ride of fluctuating hormones taking place within. Whilst the physical recovery may be quick, I believe the emotional side of things can take a lot longer.



### Nicole's story:

Nicole is dyslexic and shares her story of baby loss with us.

'Having had a MMC in 2022 I was given information about next steps and having just been told 5 minutes early there was no heart beat I was in total shock. I struggle to retain information as my dyslexia affects my short term memory and I can only hold a one or two pieces of information at a time. So I left the hospital not feeling confident about what I had just been told. I did however get given some leaflets about next steps and one of my friends came round and we went through this together.



I rang the ward and I was passed from person to person a few times, I'm not the confident with pronunciation as I say words how they sound, I'm very lucky that one of my friends took over ringing the ward for me to advocate as I find it hard enough to express what I want to say using the right terminology. On the day of my procedure the staff were great and explained everything to me, I didn't feel the need to have to tell them I was dyslexic as I was satisfied with the explanation of everything and the signing of consent forms.

I had to return to the hospital a day later for a scan at the EPU requested by the surgeon who carried out my procedure. The consultant and the sonographer spoke among each other in medical terms, which is fine as they said they would do this, they then told me everything looked ok and as it should for 1 day post D&C and didn't look as though I would need further treatment.



A few days later I got a letter through the door from the findings of this scan and there was so much information on there that I had to google, as I hadn't been told in my scan any of this information, one of them been a tilted uterus but worded using medical jargon. All of this was new information to me. This had me panicked and googling to see what it was and if this was a cause of my miscarriage. I spent ages googling all the other stuff on the letter that really wasn't neurodivergent friendly and still been in such a bad place from my loss just added to my anxiety and worry.



## Alison's story:

### Miscarriage.

That is a word I struggle with because, for me, it has no appreciable emotional content. Though I realise for other people it is a major, if not pivotal experience. Traumatic, devastating, incomprehensible loss.

My first son was born in January 1988, following a very difficult and emotionally draining pregnancy, culminating in an emergency Caesarean Section to save his life. It should have been a joyous occasion. But I recall watching the other mums in the ward doting on their babies and I just felt bereft. It was as if my world had changed forever, and I simply could not accept that.



Don't get me wrong. As soon as I found out I was expecting him, I was OK about it. I say 'OK' because I could not describe myself as happy. I was in a bad relationship, knew I would have to be a single parent, was trying hard to hold down a job in nursing and, above all that, I knew my mother would be absolutely disgusted. For 7 months I endured her tears, rants, disgust, and shame. And the added disappearance of my son's father did not help. I had little support and felt very much alone. I realise now that I was absorbing all the emotions of the people around me, mainly from my mother. So, my experience of pregnancy was devoid of the happiness I watched other people experiencing. When he was born, I went through the motions of caring for him physically. I did love him, but it felt very odd. I felt disconnected from him. It was as if it was me and him. Not 'us.' This has continued throughout his life (he is now 36, married, no kids).



I still grieve for the relationship I could have had with him but have accepted it never will come. Having been diagnosed ASD in 2024 at the age of 57, I now realise my experience of motherhood isn't wrong. It is just unlike that of those other parents around me. My son is a well-rounded, sociable man with a steady job and a very understanding wife. I am happy about that. But I do think he had to find his own way through the added difficulties of having an autistic mum.

My second pregnancy ended at 10 weeks. I realised I was pregnant at about 6 weeks. I recognised the signs. And, like my first pregnancy, I had extreme morning sickness from very early on which confirmed my suspicions. I was distraught about being pregnant. It was only a year since my first son had been born and I really could not cope with another infant at that time. But I do not consider abortion an option, so when the bleeding and the pain started, I was relieved.





I felt awful, mainly because other miscarriage sufferers were left devastated by their losses. But not for me. I felt bad (not guilty) about feeling relief! Saying that now, 35 years later, is still hard. I find myself smiling at the memory. Not because I am happy, but because with hindsight, it was the right thing for me at the time. I now know that my autism can prevent me expressing the correct emotions ... or at least the emotions which neurotypical people can understand. 35 years ago, I waited for a few days before seeing my GP. I explained what had happened and he said it was probably for the best. To me, that was perfectly fine. Now I wonder if he too was autistic.



Pregnancy no3 ended at 8 months giving birth to my second son. It was, again, a very difficult pregnancy, not made easier by chickenpox at 9 weeks, regular in-patient obstetric care due to bleeding and pain, and resulting in a 35 weeks delivery by elective Caesarean Section, SCBU, loads of staff in the very small but very bright and very loud operating theatre and an experience I would NEVER want to have again. It is best I do not go into details but suffice to say autistic people can have strange reactions to medication. The spinal anaesthetic did not work fully and, well, that is enough said! I had discussed with the surgeon that I wanted to be sterilised while I was 'opened-up' because I could not go through another pregnancy. He agreed, providing all went well with the birth. Phew! No more pregnancies! Luckily, my partner was incredibly supportive but had a health crisis of his own during the pregnancy, which left us both reeling. My son was diagnosed as autistic at 7, which led to both me and my partner being diagnosed later. So, life had its challenges.



I recall being happy about his birth and felt 'complete.' It was much easier to be a mum to him because I had help. And luckily, my son has grown into a resilient man with a good job. Sadly, I have watched him struggle to be an ideal caregiver/parent/dad to his own daughter. He questions his parenting abilities often which is difficult for me to process because he is doing a much better job than I ever did! Pregnancy no4 - the one that should NEVER have happened! A year after my second son was born, I found myself feeling horrendously nauseous again. I just knew! Took the test, realised I was about 6 weeks pregnant and cried uncontrollably. It should never have happened, and I wanted to kill the obstetrician that had done the Caesarean and sterilisation procedure! I was in a complete meltdown about the whole thing, though I did not recognise it as a meltdown at the time. I was utterly devastated that someone had done this to me. Not the bit about getting pregnant. I never once blamed my partner for that.



At 7 weeks, the physical pain overtook the emotional anger, and I delivered the mass of cells into the bathroom loo. In his distress my partner scooped it out, put it into a jar and we drove pretty darned quick to the GP surgery. I say 'it' and 'mass' because I could not distinguish a form or a foetus within the mass. The GP confirmed it was in fact the remains of an early pregnancy and booked me a gynae appointment immediately. When the GP confirmed what we already knew, my partner and I were devastated. I did not want another child but to lose one was another matter altogether. I cried. I grieved. I experienced a feeling of deep loss. And at that point, I realised what other people go through. It suddenly became something which was beyond just me. I became part of a shared, unconditional grief. This did not last though. It soon turned back to anger and frustration, leading me to demand a hysterectomy. The emotional turmoil of pregnancy was just too much for me to handle.



So, where does all that leave me 29 years later? Well, I watched from a distance as my second son and his partner went through pregnancy and delivered their daughter safely in 2016. I knitted and crocheted her enough clothes to last until she was 2 while she was still in the womb! And then I discovered that there were groups and charities out there that needed clothing and items for premature babies, babies born sleeping and babies born very early with no ability to survive outside the womb. There was a need for items which would bring comfort to parents and families who were going through a very difficult time. I set up The Angel Crib Project and I spend a lot of my time designing and making cribs from about 12cm in length to 60cm in length. I donate all the cribs to different groups that can distribute them to parents in need, and I also make bespoke cribs to order.



I self-fund this project but have a few lovely ladies who make blankets for the cribs or donate towards costs. This is my way of giving something to those parents who are experiencing loss. My autism would not allow me to go and hug them or to offer them words of comfort or advice. But my cribs hopefully show them that someone has thought about them enough to make them feel loved at such a very sad time.