

# Neonatal loss – our journey

**Susan Spencer** Mother of Tobias and Tanesha and Founder of the charity NEC UK

The following article is deeply sad and many will find it traumatic. Sixteen years ago Susan Spencer gave birth to Tobias at just 30 weeks' gestation. Sadly Tobias developed necrotising enterocolitis (NEC) and died. Tobias' unique

journey with NEC is described through the eyes and heart of his mother. Here, Susan shares her personal and moving story in the hope that her reflections might be insightful for neonatal healthcare professionals.

**W**hat shines through so strongly among the majority of neonatal healthcare professionals is how much you genuinely care for the babies you look after. For us parents, the care and support you provide is so important and has lasting impact. If love and professional efforts alone could have saved Tobias he would be here today. I think it's to your credit that you are so willing and keen to hear from families about our experiences and to listen to our voices to help shape the future.

Tobias really was such an inspirational and beautiful little boy and I want to share with you my own experiences because sometimes it feels as if there are so many well-intended assumptions out there but, just like NEC, the circumstances are very individual and what's helpful and appropriate for one might not be for another.

In sharing my experience I do so as an individual, which may not always be representative of other parents' views. I hope this may offer some useful insight into our journey.

## Tobias' early arrival

I'm so glad I was listened to by healthcare professionals prior to Tobias' early arrival and even at times when I couldn't be very specific – I just didn't feel right. I had issues throughout my pregnancy that led to numerous admissions before becoming a 'resident' patient. I am glad I was on the ward when I went into premature labour; this allowed both Tobias and I to receive early intervention, which I believe had an enormous impact on him being born in such good condition and my physical health too.

Before Tobias' birth I was shown around the special care baby unit (SCBU). This was an enormous help, however, I did not see the intensive care/high dependency unit and this seriously impacted on my understanding of what we would face. I think it would have been very helpful to have had a tour of this area if possible – to have it explained to me that this specific section was very different and more 'intense' than the SCBU I'd been shown around.

Having your baby taken to the neonatal unit immediately after birth is very hard. The separation leaves you feeling so incredibly empty, torn and scared. I was given a photo of Tobias but this was several hours later, once I'd already been transferred to the postnatal ward.

## Struggles with the breast pump

I think if I had been given his photo sooner, while still on the labour ward perhaps, it might have helped with breast milk expression. That and information on how to express, with collection cups and maybe a pump, would have been useful. I didn't initially have the deposit for the breast pump kit. Our



In memory of Tobias.

hospital discouraged patients from keeping money or valuables beyond a little loose change, so the necessary £20 wasn't something I had. This would have been an absolute barrier to early breast milk expression had the nurse not thought this through and came back to allow me to pay later.

I wasn't told how to operate the pump; I set myself up. Another really vital thing I should have been given was a realistic expectation on what I could hope to produce. I sat 'on the pump' less than 12 hours after giving birth waiting patiently to fill a collection bottle with breast milk to the same volume as a pre-made bottle of formula. I was heartbroken and felt like a failure when the maximum amount of colostrum I produced wouldn't even fill a syringe, let alone a bottle.

## NEC

I really wish that I had known about NEC. The knowledge would have helped me so much in both the short- and long-term. I also needed to be told of the benefits of breast milk to NEC. This would have been a massive help; importantly I needed to know too that breast milk doesn't make babies immune to developing NEC. As a parent I continue to be curious about what the long-term outcomes from NEC could have held for Tobias, especially after so much of his bowel had been damaged.

I have recently been watching the BBC documentary *Tiny Lives*. There is a scene in episode two where a mum of a premature baby is spoken to by a well-meaning doctor and the information he gives the mum was very similar to my experience. It was anticipated that all Tobias needed to do was grow, hold his temperature and learn to feed. Just these three

things. There was an enormous culture of positivity and hope. So much so that even though I was so scared when Tobias became suddenly unwell, I thought it would be fixable. After all, this is the place where miracles are shared all over the walls of the corridor. The thought of my baby dying just never entered my thoughts. Despite the knife edge you live on in the NICU, I truly believed we would be leaving the unit with a living baby, irrespective of how long or how difficult the road ahead might have been.

In the documentary a nurse tells a parent the journey will be a rollercoaster with lots of highs and lows. I feel we should be very cautious about offering outcomes that cannot be entirely predictable or guaranteed. Not all parents will get a happy ending.

### Transfer to another hospital

Tobias was transferred to another hospital for surgery. At the time he was being prepared for transfer my own hospital discharge was taking hours and I desperately needed to be by his side. I wasn't allowed to travel in the ambulance; I had to make my own way across town. A map, directions or even a postcode and/or unit telephone number would have been incredibly helpful. Once I finally arrived at the new hospital I was directed to the family services office to obtain the keys for parent accommodation as the accommodation office closed at midday. Again, the deposit for keys was not something I had on me in this emergency situation. By the time I actually got to the NICU Tobias was in surgery. I never again saw him conscious or with his eyes open and I regret this tremendously.

Prior to his surgery, I was not told that Tobias could return with a stoma. In fact, he did not because his bowel was too destroyed and in the bigger picture his survival was the priority. Looking back, I think I would have been quite shocked to see a bag attached to him without having even a basic understanding of what this was, or what it meant for him.

### Tobias' passing

We discussed that Tobias was sadly dying and a decision was made to withdraw his life support rather than prolong his pain. Our relatives arrived and they were understandably distraught. While my arms were holding Tobias they couldn't reach around my distressed family and one nurse hugged my 84-year-old nan who was in tears. When my brother fell to the ground crying outside Tobias' room I'm told a nurse caught him and just held him. Thank you so much for reaching out to my family too.

Tobias' dad found the situation and environment extremely difficult. In his culture the women unite and the men do the other essential things at home, including going to work. Although hard on me, his decision was entirely respected, however on numerous occasions healthcare staff assumed that I was a single parent. This was also sadly evident in the letter offering condolences and inviting 'me' to return to the hospitals if I wanted to discuss what had happened to Tobias. The latter further reinforced Tobias' dad's belief that this wasn't something he could or should be involved in.

### After Tobias' passing

Following Tobias' passing I wasn't strong enough to help do his cares and a nurse supported my sister to bathe, dress and help

take hand and foot prints. Thank you for allowing my sister to be an aunty to Tobias; both of us cherish the memory that she was able to show her love for him in this way.

After Tobias' passing, I wanted to go back to our local hospital and the staff on the NICU moved the earth to make the transfer possible. The NHS couldn't fund an emergency ambulance to repatriate us as Tobias had died. Two neonatal nurses offered to drive us in their own car but a senior manager stepped in and authorised funding for a private ambulance to take us 'home'. I'm forever grateful for this and also for the nurse who came in to Tobias' room with a jacket, blanket and a car seat. The nurse accompanied us on our return and when we arrived at the local hospital another neonatal nurse was waiting at the entrance of the maternity unit to welcome us back. She supportively walked us up to the neonatal unit with my baby 'sleeping' in his car seat just like any other newborn. Thank you for not hiding us or taking us through a back door; thank you for allowing me to experience walking through those doors with my baby in a car seat too. Thank you for enabling me further to be a mummy who was filled with pride during such a heartbreakingly distressing time.

Once we were in the rooming-in area I had no idea what to expect in terms of how Tobias would be in the coming hours with the natural changes that occur, nor did I know how to communicate with him. I'd never seen anyone who had died before and that for me was really scary. The doctor who had worked relentlessly hard trying to save Tobias before his transfer came to visit. She sat beside me on the bed and asked if she could hold Tobias. She cradled him facing her on her knees and spoke to him exactly as she did when he was alive but now with genuine emotional words of the sadness of his outcome. This brought huge comfort to me and I wasn't offended that she was upset too – if anything I felt we shared how awful this was for everyone, including the staff on the unit. She gave me the confidence and strength to get through saying goodbye, particularly in picking Tobias up and just talking normally with him. Later a nurse came and invited me to choose some clothing for Tobias; she helped wash him and dress him. She then did something I'm so thankful for to this day – she offered to take a photo of us together. She said to me: "Susan, smile with your beautiful baby boy," and with my tear-stained cheeks I did. In that moment this nurse had shown me there was no right or wrong way to grieve and that it was ok to be a proud mummy too. I very much regret that I have less than a handful of photos of Tobias and all but the first were taken when he was dying. I wish we had made more memory keepsakes before he became critically unwell.

I stepped outside of the unit for a breather when another nurse from the ward approached me. She invited me to return to the ward for my meals. While this was a kind-hearted gesture, the one visit I made caused so much distress that I left and didn't return. Breakfast was served in the day room, a place where excited and exhausted new mums shared the joy of their new arrivals; some wheeled their cribs in to the room too. The neonatal unit is an entirely different environment; the parents are all in the same boat. Its common ground, an experience we know without needing to speak words, despite the different outcomes or durations of our journeys.

## My wishes

After I'd said goodbye to Tobias I collected the green NHS patient property bag that held the contents of a precious little boy's life and I left, waiting outside for a taxi to collect me. I didn't even know if I had enough change to pay for the taxi. The world kept moving when mine had stopped and in hindsight I wish Tobias' belongings hadn't been in a carrier bag. I wish too someone – anyone – had enquired and possibly supported me to get home on that particular journey.

I wish I'd had some basic knowledge of what I needed to do next in practical terms. I registered Tobias' birth in a London borough one day and his death in another the next day, all while bleeding and leaking milk. In fact I could have done both in one office and I wish I'd known I could have called to arrange an appointment and given the registrars the heads-up of what I was about to do so as to avoid the waiting and the congratulations in a room with newborn babies crying in their car seats.

I wish someone had told me I could see Tobias again before his funeral.

I wish someone had told me I could donate my breast milk. I wish I knew how to cope with being a lactating mum, beyond taking paracetamol and putting cabbage leaves in my bra for comfort.

I wish a midwife had visited me at least once to check on my physical and emotional state.

I wish I hadn't been given so many leaflets in the hospital that were entirely irrelevant to a baby born so prematurely. I didn't need to know at that point about car seat safety or safer cot sleeping, for example. At home these were a minefield to search through when seeking some type of information that could actually help our situation.

I wish that a midwife hadn't offered me a Bounty bag at the point of my own discharge when Tobias was being transferred. My details were sold to many companies and I was bombarded with baby-related information, corporate congratulations, milestone and development moments and coupons for at least the first 12 months after my loss. It was near impossible to stop this no matter how many distressed calls I made pleading for it to end. I also received correspondence from the trust which hadn't noted on its system that Tobias had died as it had occurred out of the district.

I wish people wouldn't tell me that my babies are angels looking down on me. Individually we are all entitled to our beliefs but we should respect that others may not share or wish to adopt these. My heart aches so much when I hear people refer to babies as fighters, warriors, heroes and such like. To me it suggests that the babies who died didn't fight or battle as hard as other babies and that's heartbreaking for a parent to hear. I understand the right and wishes of other neonatal parents who may wish to use such terms, but it saddens me when professionals do it or when unit/hospital social media posts use this terminology. Every baby who requires intensive care fights and battles with all their might. There are no winners or losers exiting the doors of a neonatal or paediatric intensive care unit.

## After Tobias' funeral

It was after Tobias' funeral that I found I desperately needed the most support, yet sadly this wasn't something I knew how to

access. As simple as it sounds now, I never thought to visit my GP nor had the physical strength to do so. Those I knew didn't know what to say and kept their distance; many disappeared entirely. Those who remained felt I should pull my socks up and move on just weeks after the funeral; they didn't have a clue. One person told me she didn't want to be around me because I bring a negative vibe.

NEC left a million unanswered questions and this added to my despair because I couldn't understand it and this was so important for my journey. Healthcare professionals were so reluctant to tell me anything more than very basic information and this was not enough for me. Had I been told that nobody knew the answers to my questions it might have been easier. All these years on, there are still some unanswered questions but that's ok now because the complexities of NEC have been explained to me.

Nine months later I had a stillbirth and this pushed me over the edge. I became suicidal and it takes considerable strength to climb back from being at the lowest point you can possibly be. Meeting other parents who had experienced loss was the first step to climbing up again. The only thing I can really add here is that everyone expected me to know what to do or how to behave because I'd been through it before, but I didn't. Stillbirth and neonatal loss are often linked in the same sentence but they are entirely different, as were my needs and bereavement paths. With Tobias, being on the neonatal unit once he died was exactly where I needed to be. With Tanesha, the bereavement suite on labour ward was the most appropriate environment at that time for me.

At a medical conference last year a well-meaning healthcare professional came to speak with me. He asked about my baby and I told him very briefly that sadly he didn't survive NEC. He expressed sadness at hearing this and thanked me for sharing. He then went on to tell me that I was still young and I could have more. Such comments are a regular struggle. I really wish I could be acknowledged just as being Tobias and Tanesha's mum without people voicing another baby is what I need.

As a singleton loss parent I felt entirely excluded from the neonatal units and the neonatal community as a whole; I felt stripped of being recognised anymore as a mum. While some parents can't face being anywhere near the unit after a loss, I really wanted that engagement. I wish I'd been invited to former parent gatherings and events and given opportunities to talk, share and be around others who knew what a neonatal journey was like. I too could hear the sounds of the monitors in my head when I returned home, and to this very day I too freeze when a blue light emergency ambulance speeds by. I would have liked to have stayed in touch and followed the journeys of other families I'd met on the unit or have had an occasional chin wag with a staff member who cared for us and knew us. Inclusion matters but the decision to accept or decline such invitations is individual. It's not insensitive to ask if done the right way and with compassion.

Tobias isn't an exceptional case, the one in a blue moon that just sadly didn't survive or left the unit with complex needs. As we celebrate those who do leave the unit, I feel we should just as openly be able to honour those who don't.