

Saying Goodbye

Planning a farewell ceremony and coping with the loss

By Shelley

During the past two weeks, my husband and I have unexpectedly read endless amounts of information in our search to make sense of what has recently happened to us – medical reports on chromosome disorders that previously we knew nothing of, heart-breaking recounts from trisomy affected parents and endless literature from ‘not quite right’ help organisations. We have encountered, however, very little on how to deal with the aftermath of an elected termination following a diagnosis of Patau’s Syndrome and, so, despite the pain this causes, have decided to share our experience in the hope that it might help others to find their way through a dark and difficult time.

On April 23th 2008 we received the devastating news that the beloved baby we had carried for the past fifteen weeks had a terminal condition and would, almost inevitably, not survive birth. Our hopes and dreams lay, instantly and cruelly, smashed on the vinyl hospital floor, as the consultant explained that our baby had a range of symptoms indicative of holoprosencephaly and Patau’s syndrome - conditions which we knew nothing about and had never heard of before.

We were shown on the scan how the brain had failed to develop and listened in horror as a host of other abnormalities were described. A recommendation was made for an immediate termination. In a state of shock, but driven by a sense that the only thing we could now do for our baby was to ensure that he would not suffer any further pain, we agreed and the operation was carried out two days later.

The termination was scheduled for early on a Friday morning. This meant that I had to be admitted to hospital the previous evening. Without doubt this was the worst night of my life. Hour after hour, I had to fight my every motherly instinct to protect the life inside me and wanted nothing more than to escape the ward and find somewhere safe for us to hide. Despite this, I could not stand the thought of my little one suffering because I did not have the strength to let him go. Fortunately, the nurses and doctors were moved by our situation so let me have a room on my own and allowed my husband to stay by my side. He was an angel – holding me close and helping to chase the dark thoughts away. I would not have made it without him.

Afterwards, we fell to pieces. The ward sister came to speak to us about funeral arrangements and our initial reaction was that we wanted the hospital to undertake this on our behalf. We could not comprehend any level of involvement nor face the reality of what had happened to us. We drove home feeling numb, empty, and petrified of the world.

Several dark days followed. Then a need to take positive action began to grow. I am naturally someone who seeks solace by engaging my mind in a practical way when faced with adversity but found myself able to concentrate only on activities directly related to my baby.

The trigger was a phone call, made by my husband, to the hospital, concerning the cremation arrangements for our lost one. He explained to me that the ‘next cremations’ were to take place in over a month’s time. I could not comprehend my

little baby lying somewhere in the hospital for another five weeks and felt compelled to rescue him. Moreover, the way that they had spoken, generally, in plural terms of multiple cremations made me feel repulsed. Our child was much wanted and loved; his departure from the world had to be special.

We started to discuss arranging a cremation ourselves and realised that, actually, we wanted the opportunity to say goodbye in our own special way. I would always recommend reflecting on this for a few days before making a decision. Your initial reaction is made in a state of confusion and turmoil and, with a few days distance, you may feel differently. My husband contacted a kind funeral director who was incredibly sympathetic. He asked our baby's name. Up until this point, we had jokingly called him 'Pipsqueak'. It felt wrong to change this now so little Pip he will always be.

I regretted more than anything that I had never been able to hold or kiss our little Pip. I couldn't stand the thought of him being placed in a dark, empty box and so decided to make a cuddly toy and blanket to comfort him and express my love. I spent two days sewing a rabbit, who I named 'Mr Flopsy Angel'. I wanted this to contain as much of us as possible so I made it from two of our old t-shirts, stuffed with prayers, messages and locks of our hair and stitched a special message across his belly. I had made 'heart necklaces' as wedding favours for our celebration the previous year and wrapped one of these around the rabbit's neck. I made him wings so that he could carry my baby to Heaven or on his journey to see the beauty of the world (which is how we like to think of it).

I also made a special blanket to cover our Pip and keep him warm. Again, I embroidered a message of love on this. I like to think of this as a 'magic blanket' that will take him on many adventures. Before the cremation, we gave these to the funeral

director with a list of instructions stating how these were to be used. This sounds morbid but it gave me great focus and comfort.



The night before our 'Goodnight Ceremony', we sat down to write our service. We are not religious and had, previously, written our own wedding vows. We wanted this to be in the same style, from the heart. I will not lie - we sat on the sofa and broke our hearts as we tried to express in words the love and sorrow we felt. Afterwards though, we experienced a sense of calmness and peace. At least we were going to have the opportunity to tell Pip how much we loved him and how much we were going to miss him.

The morning of the ceremony, I woke very early and busied myself making a heart-shaped flower bouquet and small bunch of tulips for the coffin. It was important to me that I had personally contributed to every aspect of our saying goodbye. We drove to the crematorium in a blur, feeling like our hearts were being crushed by an icy vice. The sense of despair on seeing the coffin was initially overwhelming and I thought that I would never find the strength to say the words that I had prepared. Have faith in yourself though – there is an inner courage that can be found, even at such painful times.

We stood at one end of the long chapel, holding each other and touching the box in which our baby lay. I read a perfect picture book that I had bought a long time previous, for our first child. I whispered the

words as the tears streamed down my face but knew that this was the only story that I would read our Pip. I wanted to feel that we were putting him to sleep, just as if we were tucking him up in bed at home. I read my 'vows' and so did my husband. We were both very proud of the beautiful sentiments that we had expressed and memories that we shared. We said our final 'good night' and stepped outside, into the sunshine. It had, literally, rained for days and now the warmth of the sun kissed our cheeks. We took this as a good sign. Our special baby was smiling down on us, urging us not to be sad. He had his magic blanket and Mr Flopsy Angel to keep him safe and wanted us to continue to love each other and pursue our dreams.



For our wedding, the year before, we had purchased a box of large paper lanterns (available on the internet). We had sent these into the sky in celebration of our love. On the evening of our baby's 'Good-night Ceremony' we wrote our messages of love, sorrow and remembrance on one of these lanterns and sent it to him in the sky. The night was, unusually, still and, as the lantern floated into the distance, we knew that Pip was at peace and could hear us.

When such a small baby is cremated, there are no ashes. We wanted a way of remembering our Pip without tying him to a specific place with a static shrine. As such, we decided to adopt an animal, in his name,

each year. We would have a plaque that we could visit, somewhere new, each twelve months. A few weeks ago, we had visited Exmoor Zoo and I had delighted in hand-feeding the wallabies. I adore animals and knew that any child of ours would too. This made our decision easy – this year these would be the creatures to benefit in memory of Pip. It made us sad to receive the adoption certificate but we are looking forward to visiting the zoo and seeing our baby's plaque.

Almost immediately, following the termination, we knew that we wanted to make a 'memory book'. During the first few days, I was extremely scared to leave the house but managed to travel into town, with my husband, to purchase a beautiful photograph album (the nicest ones are amongst the 'wedding sections' of 'upmarket' card shops). It was magnolia canvas decorated with a simple heart made of pearl shells. We filled this with dedications, the scan photos and pictures taken during all the trips and weekends away that we had been on with Pip. Again, it caused a great deal of pain creating this but I believe that this is part of the healing process – it helps to come to terms with what has happened. We added the adoption certificate from Exmoor Zoo, when this arrived and plan to add to this, with others, each year. This will always be our most special book and we hope, one day, to share it with our children, should we ever be blessed.

The final way that we wish to honour our baby's memory is by fund-raising and doing all that we can to help and support parents faced with the same diagnosis as us. We discovered SOFT, by searching the internet, the day after returning from hospital and found their publications a great source of comfort. It helped to read people's experiences of Trisomy and discover that they had given birth to other healthy

children. We also contacted one of the charity's 'befrienders' and speaking to someone who had lived through a similar experience helped give us the strength to carry on. As a means of showing our gratitude, we are now planning ways of raising money for SOFT. My first attempt has been to ask that my friends and family give me contributions that I can forward instead of a birthday present next week.

Facing up to the reality that you have lost a much wanted baby is never going to be easy. However, we believe that your emotions should be confronted and dealt with in the way that best suits you. Bottling up how you feel will only cause you more difficulties in the long term. Share honestly and openly exactly how you feel with those closest to you and make decisions as a couple. The measures that I have described here simply represent the journey that we needed to take and you will undoubtedly have your own beautiful ideas about how to celebrate and remember your baby. Don't be afraid to experience some pain in pursuit of these and do not be deterred by what other people consider 'appropriate'.

Our Pip will always be the beautiful, amazing, little baby that we watched with delight at every scan. He will never feel rejection or pain. He is asleep now, like a good little boy, and will always know how much his mummy and daddy love him because we did all that we could and plan to continue to do all that we can to show him.

There is nothing special about us. We just have big hearts and acknowledge how these are feeling. We know that, should you want to, you can also find the strength to remember your baby in a variety of amazing ways. It helps, like a small, but growing, beacon of light.



Post Script

It is Saturday the 18th July 2009, fifteen months since our little Pip left us to play with the angels. Lying in my arms is our beautiful daughter, Amaya, born three and a half months ago. She is perfect in every way. I spend hours each day, gazing at her, thinking how amazing she is and how lucky we are. Her smile melts my heart and I feel complete in a way that I never did before.

Despite the consultants telling us to wait six months, I quickly fell pregnant again, knowing this was the only way to heal our broken hearts. It was a very anxious three months, waiting to hear that Amaya did not have holoprosencephaly like her brother (the eventual diagnosis we had received as a result of the genetic testing conducted). We remained positive though, and, even when we were shown her 'normal' brain development at the scans, didn't dare believe all was fine until we held her in our arms.

I am sharing this to give hope to those who have had a similar experience to us. Have faith and the dark clouds will clear. It takes courage to try again but that inner strength is within us all. If reading this as a sibling, born following a similar tragedy know that you have mended your parents' hearts and made the world seem beautiful again.

Pip will never be forgotten, I pray for him every night, but I am happier than I have ever been to be a mum at last.

