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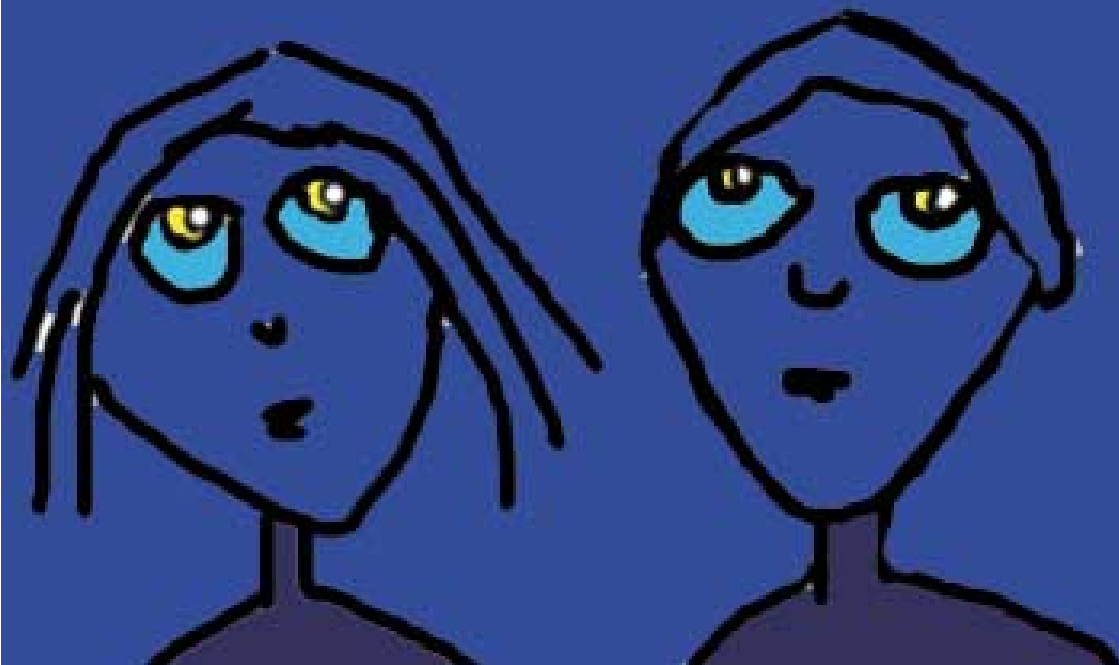
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Henry





Dedicated to the *memory* of our beautiful baby boy
3.9.98 - 16.9.98

Henry was written and illustrated by Sue Wilkinson, designed by Anthony Faure
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A Great Life



Anthony and I had a great life. We both had good jobs, he a manager within an advertising company and myself a teacher of intellectually disabled students. In my spare time I painted and had several successful exhibitions. We were social people, getting together with our friends regularly. We went to the movies often, saw a show now and again and had many cups of coffee and meals at our favourite cafes.

We had a house fifteen minutes from the city and over a few years had completed some renovations. All in all we were normal people leading a normal life. Anthony and I wanted a family, we were in our early thirties, we waited until the moment was right.

One weekend we went to Warrnambool. It was lovely being there amongst the greenery and near the ocean. It was there Henry's life began. Two weeks after our trip I began to feel sick. I made an appointment with my doctor. There,

I had a pregnancy test. The lines on a simple urine test confirmed my suspicions. I was pregnant. The doctor hugged me, then sat me down. I continued to look at the test. I was incredibly happy. This was my first pregnancy.

The schedule was set. I was due November 18th. It seemed so very far away. I drove straight in to see Anthony at work. I bought chocolates and told him. He was ecstatic. We told our families immediately – we were bursting to share our good news. They were all so happy for us.

I didn't drink or smoke, I avoided our cat and watched my diet. I read everything in sight. We started to create a nursery, looking at furniture and baby goods. Having a baby consumed our every moment together. We talked constantly about plans, the nursery and the birth. Together we looked at hospitals, and decided upon a birthing centre at a local public hospital. We wanted a minimal intervention birth.



The Three of Us

Anthony pampered my every need. As the pregnancy progressed I rested in the evenings instead of going out. We enjoyed our time together, the three of us.

I went along to my regular doctor and midwife visits. Everything was normal, or so I thought. At 18 weeks I heard the heartbeat. I cried. I was so happy. Anthony came along to each ultrasound with me. At our first ultrasound we were so excited. On a small monitor we saw our baby moving inside me. We were reassured that everything was normal. We watched the

ultrasound over and over again at home. On our second ultrasound we found out I was carrying a boy.

In the 29th week we attended our first ante natal class. We met other expecting parents. We compared bellies, expected dates and pregnancy stories. It was such an exciting and informative evening. We went home buzzing with excitement.

The Roller Coaster



It was difficult to sleep the night after the antenatal class. I thought it was a mixture of excitement and worry. I complained to Anthony of a rough night. I had a shower and got dressed. My belly seemed even bigger than normal and the baby seemed high, almost under my ribs. There was a trickle of fluid down my legs. It was then the roller coaster scooped us up. I contacted the Family Birthing Centre and after a short question and answer time the midwife instructed me to come into Emergency.

We navigated our way through peak hour traffic. It was so incredibly frustrating being stuck behind trams, trucks and cars. We did our best to remain calm, but the fluid was trickling out each time I moved slightly. We eventually made it to the hospital. I got out, Anthony parked the car. I walked towards reception holding my hands between my legs. I was now terrified. The nurses at reception asked my name, it was difficult to speak. I was helped into a cubicle and Anthony

rejoined me. Within minutes I felt an incredible surge of fluid.

The nurses were great. They strapped a heart monitor to my belly. We heard the heartbeat. It was strong. A doctor was quick to examine me, she told us that there were a variety of possibilities now that my waters had broken. Labour may begin, an infection could develop signalling the need to get the baby out of my womb, or the baby could remain safely in the womb for the next eleven weeks. It was obvious now that every hour the baby remained in my womb would be considered a bonus hour. It was an incredibly confusing time. There were so many new faces, medications, procedures and technical terms. Our minimal intervention birth plan was now in the wind. I was given an injection of steroids to aid the development of the immature lungs, antibiotics to fight infection and was put on an IV drip.



Shock and Confusion

The next 24 hours were incredibly difficult. I had an ultrasound, but due to a miscommunication, I was rushed to delivery suite for the impending birth. Anthony held my hand and stroked my face. The cervix was thought to be dilated, but was not, and the rush of faces into the delivery suite settled. The baby was not going to be born at this stage. It was difficult to remain calm.

Twenty four hours passed by slowly and I was given a second steroid injection. I was now on a drip of ventolin to help ease the pains I was having. The ventolin did ease the pain, but added to my feelings of disorientation.

I was moved to a ward where it was possible to stay for the duration of my pregnancy, however long it may be. I started to feel a little more confident. Anthony and my parents were very reassuring but we were all so shocked. Prematurity was not known in my family and

the pregnancy had been progressing normally. When the ventolin course was complete the pains returned. We timed them. A nurse helped me through each pain. The decision was made to move me back to delivery suite.

More new faces introduced themselves, in the end I had no idea who was who. A surgeon spoke to me briefly and told me that he thought the baby needed to be delivered. An infection had developed, I was moved to theatre for a caesarean. I was in a lot of pain and extremely frightened.



Little Purple Baby



Anthony sat beside me, we looked deeply into each others eyes. I could see his fear, but he smiled through his anxiousness. We were silent. I was confused and disorientated, I relinquished control. I was now in the hands of Anthony and the many people who filled the room.

The surgeon began the procedure, and within minutes I looked up to see a little purple baby. Our baby. Our son. He weighed 1600 grams and was 40 cm long. My heart was filled with such love. He was so beautiful. I reached out to touch him, but without any co-ordination my touch missed.

I had been prepared for the situation of not being able to hold him, but it was difficult. Our moment of joy turned to fear quickly. We waited to hear his cry. He never did.

In the corner of the room a team of people surrounded him. The voices I could hear were distorted, and I was unable to see what was happening. I could hear a strange hissing of air, and knew that they were trying to get him to breathe. I wanted someone to tell me what was happening, but was willing to wait until someone had time to explain everything.

Anthony and I continued to look in each others eyes. We were so confused and frightened. We waited. The sound stopped, the voices continued. I felt a chill run through me. The surgeon continued and after several long minutes we saw Henry, alive, in a humidicrib, and on his way to the hospital neonatal nursery. Anthony was asked for his name. Henry James was given an identity.



Sorry Eyes

I was moved to a recovery area, Anthony rejoined me and together we waited an eternity to find out how Henry was doing. We feared the worst. The paediatrician came and stood by my bed, he had the 'I'm so sorry eyes'. The look that says 'prepare yourself, I have something horrible to tell you'. He told us that Henry was very sick. 'Sick', I thought, 'He's alive, he's alive!'. My mind was dancing, until the music stopped and I started listening again. Sick? How sick?

Whilst in recovery Henry had been given an X-ray. It showed he had a congenital abnormality – specifically, a left diaphragmatic hernia. There was a hole in his diaphragm and his intestines had moved through the diaphragm and into his chest. His immature lungs were barely functioning, and his left lung had not fully developed because of its lack of space to grow. He was struggling even with a ventilator. We were told the next 48 hours were going to be the most difficult and there was a real possibility that he would not survive.

He was now too sick for the neonatal nursery and required transport to Intensive Care at a nearby hospital.

Soon I was wheeled down the corridors to the neonatal nursery. Outside in the hallway my parents and Anthony were crying. I thought I was too late. I feared the worst yet again, but Henry was alive and preparations were being made for his transfer. My time with Henry remains blurry.

Before Henry's transfer I saw him once again back in my room. It was difficult to see his face behind a large ventilator tube. The transport team gave us two polaroids before leaving. I was now going to be separated from my baby, not by rooms, but by kilometres. I felt incredibly sad and confused. Surely this wasn't really happening, surely I would wake up in the morning, in my own bed, pregnant.

Anthony held my hand until I fell asleep. He stayed the night by my bed.

Separation Anxiety



I woke early. I saw the hospital room. This was no dream, this was real. Anthony was still by my side. My parents walked into the room as I was waking. The smiles on their faces told us Henry was alive. They had sat by him all night. They told us about the care Henry was receiving and gave us two polaroids the nurses had taken. He looked so tiny and vulnerable laying there, connected to the machines.

We kept in contact with Intensive Care. 'Stable' became such a celebrated word. It was difficult to be so far away from my baby. The day passed slowly and we counted each and every hour. By the end of the long day we were starting to feel a little more confident about Henry's survival. We decided Anthony should spend the night at home, he had not slept for days and had been coming and going from both hospitals, he needed the rest. At 1am I called Intensive Care. A friendly voice spoke. She was the nurse looking after Henry, she asked me how I was

feeling and showed genuine concern for my predicament. She told me that Henry was no longer stable. She suggested that if possible I should come in to see him. The shake in her voice seemed to indicate that perhaps Henry was in real trouble.

I phoned Anthony and told him to come quickly. I was helped into a wheelchair. I had a catheter and a drainage bag. I was uncomfortable to say the least, but my physical pain was not a priority. I sat and waited, every minute waiting for Anthony seemed like an hour. I watched the clock tick slowly. I desperately wanted to be with Henry, hoping he didn't die before we arrived.



A Single Touch

We reached the hospital after a slow and cautious drive. Anthony wheeled me through the long corridors and we waited outside Intensive Care until we were given permission to enter.

In a large room at the end of a long corridor I saw my son. He was attached to so many machines. He had lines, tubes and things I had no idea of their name or purpose. Henry was laying on his back, his arms and legs extended to his sides.

The nurse looking after Henry introduced herself. She told me that since our conversation Henry had regained stability. I tried desperately to understand everything she said, but I was still on painkillers, and was in such a state of shock. I understood that Henry was stable, he was on life support, still within the dangerous 48 hour period, and I was unable to do anything to help him. It was incredibly confusing time. We felt such a surge of powerlessness.

I was physically and emotionally exhausted and felt so sick being out of bed, but we stayed with Henry for a few hours. A single touch reassured me. I wanted dearly to hold him, protect him, help him, but it wasn't possible. We touched his body and smelled his hair, we took polaroids. I held the polaroids to my heart as Anthony drove back to my hospital. We cried, and started to question 'Why...Why us...Why Henry?'. I was helped back into bed. I rested for the remainder of the night, calling Intensive Care every couple of hours. Anthony went home, and the night passed slowly.

We Started to Learn



The next morning was brighter. We had been informed of accommodation at Henry's Hospital. Anthony made arrangements for my transfer. I hated being separated from my baby, and at midday, only 36 hours after Henry's birth, I was discharged.

No longer on painkillers, I could see Intensive Care clearly. There were other children, on similar beds. Computer screens had lines and numbers, machines beeped and ventilators wooshed around me. It was terrifying. Reality hit and it hit hard.

I felt so helpless and stupid. I had no idea of the complications of prematurity and had never even heard of a diaphragmatic hernia. We started to learn, we asked questions and were supported by a great team of doctors and nurses. We were given as much information as we could absorb. The doctors were not confident of Henry's ability to make it through, he was faced with

two substantial problems. There was the realistic possibility that Henry's treatment could give him brain damage, blindness, deafness or more. Our love for Henry was unconditional. We wanted him to survive regardless. The doctors tried to keep our feet on the ground, but we clung desperately to hope. It was all we had.

I was producing breast milk and had been so looking forward to putting my baby on my breast. It was stressful not being able to hold him, feed him, bond with him. I was taught how to express using an electric breast pump and every three to four hours I would go into a room to express. I adapted to writing Henry's name on each bottle, sterilising procedures and storing my milk.

We started to document Henry's life. We took photos and began writing in a diary a nurse had made.



Margin of Confidence

Time took on a new perspective, and eventually the critical 48 hours passed. Henry was doing well. He had a long road ahead, but we developed a margin of confidence.

Each hour continued to crawl by, and each day lasted an eternity. We sat with Henry hour upon hour, day upon day, asking questions and learning. We watched as his tubes and lines were changed, saw him receive blood transfusions, sat with him when he was given medication to paralyse him, and listened to the sound of suctioning of the fluids in his throat. It was incredibly distressing to watch as others cared for my baby, all I could do was talk, listen and learn.

We talked to so many people, doctors, surgeons, neonatologists, paediatricians, nurses, dieticians, radiographers, ultrasound technicians. It was all so confusing.

Henry had small steps forward and some steps back, we learnt how to cope with good and bad news. Anthony and I had our maternal and paternal instincts and not the normal parenting environment, so we did what we could. We wiped Henry's eyes, held his hand and talked to him constantly. We read him stories and pulled the tail of a musical toy to distract from the relentless beeping machines and the thumping of the high frequency ventilator. We placed little soft toys in his bed. It was heartbreaking, but we kept going.

We washed our hands several times a day, and limited Henry's visitors as there was a real fear of transmitting germs. Infection was a great possibility and Henry would have difficulty fighting off any infection at this stage.

The Waiting



On the 10th of September Henry was stable enough for surgery. It was scheduled for the following afternoon. I worried all night, 'Would he make it another day without an infection? Would we miss the window of opportunity?'

My parents, Anthony and I waited in the Intensive Care waiting room on the afternoon of the surgery. We attempted to remain calm. The colour drained from our faces as we walked paces within the tiny room. We held each other. We cried, and we waited.

The surgeon had large hands and a gentle face. He told us of the procedure and relayed a feeling of confidence. He informed us of the risks, and they worried us, but we continued to cling to hope. In our minds, if Henry could make it through this operation, he would have a greater chance of survival, a greater chance of coming home.

Three hours crawled by. Henry's trolley was wheeled past the waiting room door, he had

survived the operation and was being returned to his area within Intensive Care. I was desperate to see the surgeon and after several more excruciating minutes he walked down the hallway towards us. I checked his eyes for the Sorry look. It wasn't there. He smiled. We cried.

He told us that the surgery was successful. Henry's intestines were now out of his chest and where they were supposed to be. His lungs were now in enough space to form. A thousand thank you's were not enough.

Slight colour returned to our drained and aged faces and within seconds we were by Henry's bed. A large scar extended from the centre of his chest on a slight angle to the left side of his body. It was covered in a plastic film. We celebrated his strength and for the first time the roller coaster seemed to slow a little. We were able to catch our breath.



Five More Days...

We adapted to living at the hospital, our old normal life seemed so incredibly far away. Our new life lay on a bed in Intensive Care. We ate at odd hours, slept badly and communicated by public phones with family and friends. We were prepared to live at the hospital for a lifetime if it meant we could be with Henry. There was nothing for us at home.

For five more days we watched the outside world scurry through their normal lives from large windows. We wondered when we would be able to take Henry into the outside world, away from the machines, away from the hospital. We talked about all the things we could do with him, places we would go and things we would do together as a family.

Each day signalled a little improvement and we felt confident enough to allow Henry some visitors. We began to make arrangements for the upcoming weekend for Anthony's parents to meet their grandson. We were enthusiastic for them to see our beautiful little boy.

My parents visited daily. They kept buying Henry toys and things and would sit with him each evening. They wrote in his diary and took photographs at every opportunity. The love and dedication they showed saddened me. I felt such overwhelming guilt. I felt responsible for putting everyone, including Henry through this.

I began to question my diet, my lifestyle. I wanted a reason for Henry's condition. There wasn't one to be found.

Fly Henry, Fly



On the 16th of September our worst fears were realised. Henry showed signs of an infection. The word sepsis still rumbles through my brain over and over again. Henry's usual pinkish skin had changed to a murky grey.

We were asked to sit in a nearby waiting room. The surgeon had been called and he spoke to us. He would attempt surgery if Henry became stable once more. That surgery never eventuated.

Henry's heart stopped beating. The doctors gave us five minute updates, until eventually he was stable. We refused to sit in the waiting room any longer, and told the doctors we wanted to be with our son. They were supportive of our needs, and warned us of Henry's stability and his now bruised and bloody appearance.

We cried when we saw our little boy. His chest was now very bruised, there was blood in his ventilator tubes. Doctors explained that Henry had been given heart massage and more medication. It was horrific seeing Henry like this. Guilt and fear once again consumed me.

We talked to the doctor in charge, we asked questions that we thought we would never want the answers to. We stroked Henry's body gently. We told him of our love for him. Within minutes a beep sounded that I will never forget. I looked to the monitor that I had studied for thirteen days and watched his heart rate jump around erratically. Doctors and nurses jumped into action. It was frantic, they gave more medication, altered lines and tubes and once again began heart massage. Watching those thumbs pressing up and down on my baby was incredibly distressing. I felt so helpless, so pained.

Someone in the room sat us down and gave us tissues to wipe our eyes. The thumbs kept moving up and down, up and down. Henry was not responding.

Henry was separated from the tubes that had maintained his life. He died in the arms of his daddy at 11.40 am that morning.



First Hold

Anthony passed Henry to me, his little body now limp. I held him tightly. This was my first hold. I felt the crash of my heart as it fell from my chest and onto the floor. I was oblivious to the world around me.

We went to a nearby room where we could be alone. Tears poured from our eyes. We asked 'Why Why?' and wailed 'No No No'. Henry's eyes were closed and he had a gentleness on his face. For the first time in thirteen days all was quiet except for the words we spoke and tears we shed. There were no doctors or nurses, no noisy machines.

A little while passed and a nurse helped remove the lines and tubes and peeled away a facial bandage that covered his nose and cheeks. We saw our son for the first time. We were asked if we would like to give Henry a bath. We did. We dried him gently and continued to talk to him as we wrapped his body in a bunny rug. We were so incredibly sad, so angry and so upset with ourselves. In our minds we had failed as parents.

We had watched him die. We felt helpless and useless. We hated ourselves for not being able to protect him.

My parents were called and arrived fairly quickly. Together we felt the pain. We held each other as the questions without answers filled the air. We all held him, kissed him. It was torturous. This was so wrong, so unfair, we were holding our dreams, our future in our arms, and he wasn't breathing. Nothing in our lives had prepared us for this. It was horrible.

We took hours to say our goodbyes, it felt like minutes. Leaving Henry in the room was incredibly painful. We left our hearts and love of life in that room.

The atmosphere in the normally bubbly Intensive Care was now so quiet. The staff were genuinely upset and were comforting as we were helped from the room. We were silent as we navigated our way through the long corridors back to our room. We were limp and empty.



Coming Home



Anthony's brother, hearing of Henry's death, had come straight into the hospital. Mum, Dad and Anthony's brother held us and helped us gather our things. We needed to leave. We could not stay knowing that Henry was no longer alive. We ached with grief. Anthony and I held each other tightly.

We went home. It was a long and painful drive. I was numb. Only hours ago we had been sitting by Henry's bed confident of his progress. Once home, I had a bath and put on my pyjamas. There was a cold silence. No beeping machines or ventilator noises, no doctors or nurses performing their daily duties. Anthony cried, I cried, my parents cried, Anthony's brother cried. We filled the oceans that afternoon.

I spoke to my doctor, who gave me advice on the management of my milk. The pain of my breasts added to the pain in my soul.

The thought of having Henry in a cold room alone distressed us. We wanted to organise the funeral quickly. As with so many other things over the last thirteen days, we had no idea of what to do. We never thought that we would have to organise our son's funeral. I called a local funeral director and made an appointment for the next day.

The rest of the day remains blurry.



Teddy Bear Urn

The next day the funeral director brought around a small urn decorated in teddy bears. She was very gentle with us, and helped us through the possibilities. Anthony and I had discussed everything, and decided upon an unattended cremation and a memorial service. We chose an outfit for Henry to wear and gave the funeral director a musical toy and a gold angel to be cremated with him.

That night, after an incredibly depressing day, Anthony and I prepared a service that celebrated Henry's life and showed how much we loved him. It was our job as parents to do the best we could.

Anthony and I were inseparable. We held each other and cried almost constantly. We felt the torture of organising a service for our baby. It was horrendous.

We asked Anthony's brother and a dear friend to read for us at the service. They were invited over and together we read their scripts. My parents wrote a beautiful letter to Henry and offered to read it at his service. We were so thrilled that they wanted to share such a personal letter.

We had some visitors who were kind enough to sit with us, listen, hold our hands and wipe the tears from our cheeks.



The Memorial Service



On the morning of the service it rained, but the sun somehow managed to shine between the clouds. Anthony and I went early to the chapel to spend time with Henry and set up the table. Anthony placed flowers, toys and special gifts around the tiny teddy bear urn. The sun streamed in through the leadlight windows behind the table.

Family and friends filled the chapel. We were astounded by the number of people who attended. We had asked that no children attend. I could hear continuous sobbing from every direction. Although incredibly difficult, the service was beautiful. We were rich in support. I had worried that everything would go wrong.

The roller coaster was still roaring, emotional highs and lows welled up such confusion. We were still waiting to wake up from this nightmare.

An after service get-together had been organised at Mum's, but Anthony and I did not want to attend. We had made plans to scatter Henry's ashes at Warrnambool, and wanted to do it directly after the service. We could not face bringing our little boy home in an urn.



High on a Mountain

We set off to Warrnambool. Anthony drove carefully. He had a look of sadness and determination on his face. We had wrapped the urn in a bunny rug and I held it tightly in my arms. The urn moulded to my body. It was the longest time I ever held Henry.

We arrived at Warrnambool and located a favourite place of ours. It was a mountain overlooking a lake and the ocean. We walked to the top and laid down flowers. We wept as we scattered Henry's ashes and said our goodbyes. We sat there oblivious of time, only noticing the day was ending by the sun sinking behind the mountain. We stood to go home, but were unable to leave. Eventually we had the courage to say a final goodbye and started the walk down. Lead lined the soles of our shoes. Each step was torturous. I was awash with feelings of abandonment.

Anthony pointed to some ducklings bobbing for food in a river. He said the most reassuring thing: 'Look, this is a place of love and life. It is a place of families and birth. This is the place for Henry.'

We drove slowly towards home. I needed constant reassurance. I worried Henry would be cold, lonely and frightened, it didn't make sense. I was so confused.

Our pyjamas were on our bed waiting for us, we put them on and snuggled together. We cried, eventually we fell asleep.

Life without Henry



I face real fear every day. Fear that I will forget, fear that I am unable to live a happy life and fear of losing my sanity. My whole world has collapsed around me. My dreams and hopes are so out of reach. Lost is the fun free spirit, the dreamer, the hopeful. Sometimes I feel so on top of things, able to cope and able to put on a brave face to make it through the relentless obligations and normality of life, whilst other days I find it hard to make it from one room to the next. I find times where I laugh and smile and sometimes feel guilty for smiling, for being happy. It's confusing.

It is so incredibly painful living without my son, a pain that generates from my heart and ripples through my entire soul. There is no solution, no easy way of dealing with this, no band-aid is big enough to heal me.

I had difficulty understanding how life could go on, I wanted the clocks to stop, for the world to stop spinning, life would never be the same, we would never be the same. It was so difficult watching a world that seemed relatively unaffected by our son's death.

Anthony resumed work a couple of weeks after the service. They wanted him back on deck. It took him a lot of courage to return and he struggled through the first few weeks. He put on a 'work mask' which helped him to get through each day. He divided his time into work time and grieving time. I worried he was pushing his feelings down and not dealing with them, but he was dealing with everything, in his own way. He finds some days easier than others, but manages to hold himself together.

I took time off work. It gave me time to think. It gave me time to stay in my pyjamas and hide away from the rest of the world when I needed to. Months after Henry's death, my well-worn pyjamas are stashed in a drawer. I don't need them as much now. I have started to learn how to cope, and how to live without Henry, I have started to learn to smile again without feeling guilty, I started to believe in myself again, realising that I will never forget Henry.



Band Aid Solutions

Our family and friends had so much trouble dealing with our grief. We were new people, sad people. Most admitted that they didn't know what to say or do, and in the weeks following Henry's death we somehow found ourselves educating and consoling others. We made the decision to stop helping others and help ourselves.

Some people had so much trouble they avoided us. Some rang often, others rang infrequently or not at all. Others used initiative and helped us where they could. Everyone was different in the way they dealt with us, we accepted that, but couldn't tolerate insensitive statements, questions, or band-aid solutions, that, to them offered us hope or meaning in our grief and healing. We wanted people to realise that they didn't have to offer us bandaids. We wanted people to listen, not talk. We were so appreciative to those who continued to say Henry's name and wanted us to talk about him.

Here are some examples of band-aid solutions and questions we heard.

'You're young ... you'll have more.'

The frequency of this comment astounded us. We felt it unfair and insensitive for others to think that we could simply replace or move on from Henry so quickly, and we told them.

'Why are you sad?'

We found ourselves reminding people that our son had died and we continued to feel sad.

'When are you due?'

I answered this one honestly, then went shopping for new clothes.

'Feeling better?'

Some people had no idea that we continued to grieve months after Henry's death.

‘Time will heal.’

In the first three months, time compounded our feelings. Each new day brought forward a new realisation, a memory, a new sadness.

‘He’s with God now.’

We wondered how this comment was supposed to make us feel better.

‘Keep busy.’

Keeping busy wasn’t a real solution. We needed to work through this in our own time and in our own way. Hiding or burying our feelings wasn’t an option.

Mixed in with the bandaids were great acts of kindness and compassion. People would go out of their way, showing initiative, not waiting for the reply to ‘If there is anything I can do...’

Some friends rang almost daily, one cooked us dinner, another wrote a poem, Anthony’s sister created a needlepoint, my brothers planted trees in Henry’s memory, some friends sent cards and flowers on Henry’s due date, a family friend prepared all of the food for after the service and our florist donated all of the memorial service flowers. We were also given rose bushes to plant in our garden.

We were pleased people were acting on their hearts. It meant so much that some avoided band-aids all together.



Empty

Sleeping is hard, waking is hard, breathing is hard, it's all so hard, and my arms feel empty. I yearn for my son. I grieve for him. I want my hands to keep busy to distract from the gravity of my empty arms.

These are some of the things I kept occupied with:

I wrote letters to family and friends to thank them for their support.

I made up a photo album of Henry's life.

I visited family and friends.

We practiced retail therapy ... we spent money.

I started a journal.

We went to regular counselling sessions.

I created a painting for my son titled 'Empty Arms'.

I wrote to Intensive Care and thanked them for their support.

I started writing this booklet. I had a strong urge to tell Henry's story.

I tracked down a mother of a little boy who was in Intensive Care. Her son died shortly after Henry. We met and talked and continue to support each other.

I located a Parent, Advocacy and Support Group for Diaphragmatic Hernias on the Internet.

I consumed everything I could research from the Library.

I made an album of all the cards and letters we received.

Anthony bought me a rose gold locket. I put some of Henry's ashes inside. I wear it daily.

We contacted the International Star Registry, and named a star after Henry.

I organised and donated a trolley housing a CD player, CD's and books for parents and children in Intensive Care. Engraved on the trolley are the words 'Henry's Trolley'.

Juggling Act



I became proficient at juggling emotions. Some are harder to juggle, some are heavier than others, some come and go quickly, and others envelop me. Months after Henry's death I continue to juggle.

Here are some emotions I have had to contend with. They are in no particular order.

helpless	disillusioned	adoration	anxious	confused	impulsive
stupid	distracted	confident	lost	miserable	restless
disappointed	empty	happy	grateful	failure	cautious
lonely	powerless	weary	horrified	desperate	joy
disoriented	vulnerable	courageous	caring	optimistic	failure
distressed	self-pity	defeated	possessive	sentimental	sorry
angry	regret	devoted	despair	defensive	complacent
sad	guilty	impatient	grateful	inconsolable	generous
relieved	shock	annoyed	resentment	nurturing	ignorant
frightened	love	intolerant	inadequacy	aggressive	denial
hopeful	elation	worried	tense	rejected	incomplete



A New Perspective

Having a son born prematurely in a traumatic birth, hearing a life threatening diagnosis and watching Henry undergo treatment and losing him has changed me, my perceptions, my relationships and so much more. I have come to the following conclusions.

I am still a mummy even though my son is not in my arms.

Maternal instincts don't just go away.

Most people don't know how to cope with grief. They don't know what to say or do.

Friends become strangers and strangers become friends.

Some days I cry a lot, some days a little, but I still feel the same on the inside.

Some days I am better at juggling my emotions.

Grief makes me say what I think in half the time.

Anthony continues to grieve with me. He needs me as much as I need him.. I respect that he grieves differently to me.

I am vulnerable.

I hate the roller coaster.

I shouldn't feel guilty when I smile.

I shouldn't push myself too hard.

Sympathy cards soon get replaced by bills.

Everyone you tell has a story to tell.

Not everyone is a good listener.

It's not fair, it's not right and we didn't deserve this.

I wanted to be normal again but didn't know what normal was.

Being sad isn't selfish.

I had to pick up the pieces of my life and learn who I had become.

Bubba Two



Still numb with disappointment, Anthony and I made the decision to have more children. We felt such guilt when we admitted that we wanted another baby. We talked to each other about how we felt. We didn't listen to people who said 'wait', we didn't listen to people who said 'do it straight away'. We listened to our hearts and each other, and started trying to conceive when we were ready.

We somehow thought that having bubba two would be like replacing Henry,

... it wasn't.

We thought that by having bubba two, we would be closer to forgetting Henry,

... we couldn't.

We wondered if others would think bubba two would be an answer to our grief.

... it didn't matter what anyone else thought.

We were definitely going to do things differently this time. We decided not to tell others of our plans to have bubba two. We felt our lives had somehow ventured into public property and we wanted to have some space, some privacy, some time to ourselves.

My innocence had abandoned me. I struggled waiting each month for a positive result, and then, when I eventually conceived, I worried that something would go wrong.

Here We Stand



The roller coaster rides continue to rush us though so many ups and downs, so many highs and lows and so many twists and turns. Here we stand, dizzy, disorientated and without our son. We have made it through hours that we thought would never pass, and made it through days and weeks when we thought it impossible, but we did it. There are so many reminders in and outside our home, they are everywhere in every form, from advertising to books, movies, shopping centres and so on. I also have physical reminders of my own: a huge scar, and new padding around my belly.

Three Days

Three days after losing Henry we were unable to look after ourselves. We cried constantly, didn't eat, slept badly, had little concentration and relied heavily on others for our basic needs. We managed our days hour by hour. We waited for someone to tell us Henry was alive.

Three Months

At three months we were still in shock, but we started to learn how to cope. Some days were easier than others. Life was so very complicated now. Some of the people around us were expecting us to 'move on'. We weren't ready. We missed Henry terribly and cried almost daily. We carried our heavy hearts through a loneliness that defied description.

Three Years

We haven't come this far yet. I can't imagine where we will be or how we will be feeling three years from now. Whatever we do I know we will be missing our son, thinking, 'Henry would have ... Henry should have ... Henry could have ...'