Loss Memoir

A MEMOIR OF LIFE AFTER LOSS IN A SINGLE PREGNANCY

Irish Neonatal Health Alliance

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Thank you to all the children who drew illustrations for the stories of the babies in this memoir, some of whom are big or little brothers or sisters to babies who have died.

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My Big Sister, Sharon

By Lisa O’Connor

About the author: Lisa O Connor’s big sister Sharon died 49 years ago, around the time of her birth. Lisa never met her sister and sadly at the time, society did not encourage parents to gather keepsakes however Lisa remembers her sister every day in everyday ways and includes her in her family. She feels that Sharon, as her big sister, is watching over her and protecting her as she lives her life. Lisa now wants to help more recently-bereaved parents along their journey.

By sharing Sharon’s story, Lisa is also creating new memories of her, acknowledging the impact of her life. Sharon has also inspired Lisa to spend most of her career working directly with children who have experienced abuse and neglect.

My older sister Sharon was born in May 1972. She is registered as being stillborn. She was in a breach position when she was being born, which squeezed her umbilical cord in the birth canal. This blocked off her oxygen and although the doctors attempted to resuscitate her for several minutes, they were unfortunately not successful.

It is 50 years since Sharon’s arrival into this world and thankfully things had moved on somewhat than in previous generations – Sharon was named, had a funeral, and is buried in our family plot. However, sadly my mother was not given the opportunity to hold Sharon, take photographs of her, gather keepsakes as mementos of her precious life such as her hospital name tag, her hand and footprints or a lock of her hair, which was dark and long apparently. All we have now are verbal accounts from my aunt, who collected Sharon from the hospital with my father. My aunt has told us that the handover of Sharon’s body was very traumatic, distressing, and cold for her. I am glad my mother was spared that ordeal.

When I came along, two years later, for as long as I can remember, Sharon was spoken about in our family circles. I always knew she existed, and we visited her grave regularly. She is buried alongside my father who passed away in a road traffic accident in the Autumn of 1973. I remember taking home a crystal stone from their grave after the blessing of the graves each year and it was precious object to me, which I kept safely. Over the years, although I did not pray to Sharon, like my mother did, I have asked for her assistance more than once, where I believe she has saved me from some major scrapes. She was protecting her little sister.

Although Sharon was never a secret, her little life was never fully explored until many years later, when I was training to become a psychotherapist. Through guided meditation, which explored attachment, I became distressed and did not explore my own safe birth but instead that of my sister’s, where I found it hard to breathe.

Afterwards, I was eager to find out what actually happened to her. I believe, little ones who pass do not like to be ignored, and I had found myself on a mission!

I enlisted the help of my mother who signed papers to release Sharon's files to us. My mother and I bonded over a shared interest to find out what happened to Sharon. We received her autopsy report and unfortunately timeline of events that my mother recalled, and Sharon's birth weight, were wrong in the records, among other things. Secretly, I hoped there would be a photograph of Sharon in her file. The prospect filled me with both fear and excitement, but there was not one. The report just stated the cold hard facts and was devoid of all the emotion that my parents experienced. There was no compassion for the loss of a tiny soul. This really saddened me, but I also found it to be a therapeutic experience. To this day, I believe Sharon wanted us to know what happened to her and she allowed me into the experience of her birth by triggering my quest to explore the truth.

I have no doubt my mother still has traumatic memories when she recalls my sister's birth and to this day her grief is triggered when she sees a mother with two daughters of similar age to Sharon and I. She has often told to me how she longed to have had the opportunity to raise two girls instead of one. Sharon's loss is deeply felt at family gatherings and when I got married five years ago, I felt her presence throughout the day. I put the exact same bouquet of my matron of honour on her grave prior to the wedding. I include her in everything.

When I had a suspected miscarriage in the months after I got married, for the first time in my life I understood the loss my mother talked about. The wonder of what my baby would have looked like, the colour of their eyes and hair, their personality, their interests, their firsts tooth, steps and words. It felt like been denied the fundamental right that every parent wants - the opportunity to care for and raise their child. My gut tells me my baby was a boy and I feel comforted knowing that he is being looked after by his aunt Sharon and is not alone.

Today, my sister has unfolded the truth of her existence. An angel headstone now marks her place in our family plot, bearing her full name and date of birth. The headstone we commissioned had stayed in our home for a few days. It felt like we had finally acknowledged her birth and death and had spent some time with her before letting her go to join other family members who have passed on. I implore anyone who experiences loss of a sibling around the time of their birth, to acknowledge them and to have no fear of integrating them into their life.

Be happy that they existed and feel blessed that they have graced your life even for a short time.

I know I have. **LO'C**

Receiving a medical diagnosis for my baby

By Sue Codd

About the author: Sue is married to Mick for 18 years and they are Mam and Dad to 3 precious children Finn who is 8 Loughlin who is 6 and Sadbh who would have been 3. Sadbh was born sleeping at 38.5 weeks in 2017 following diagnosis of a medical diagnosis during pregnancy. Sue found that connecting with other mothers in similar circumstances through baby loss organisations helped guide her through this very difficult and sad time. She tries to ensure that Sadbh's life did make a difference by fundraising for the charities that helped her at the time and by doing random acts of kindness in Sadbh's name.

After two easy and enjoyable pregnancies that produced two beautiful healthy boys, I was surprised that I went on to have two consecutive miscarriages. Not wanting to be deterred we tried again. I got pregnant just as easily as the previous four times but because I was 41, and had two recent miscarriages, we were cautiously optimistic. This pregnancy, as with each one before, felt easy and as we reached the 14 weeks mark, and we excitedly decided to share our news with family and friends and started to become hopeful.

Then came the big 20-week anomaly scan. I had not worried about this scan on previous pregnancies but now I worried about it following our two miscarriages. This scan was to become the turning point where our "normal" life as we knew it was about to change forever.

The scan began with my husband at my side and the midwife scanning my tummy as normal. Then a profound silence engulfed the room, as the midwife continued to scan back and forth again and again. She swiftly got our consultant who said that it was not good news and that there was a large amount of fluid around our baby's abdomen and skull and the baby may have "Foetal Acites". I asked about the baby's gender, and we were told that we were having a girl. With that we were given a referral to the National Maternity Hospital in Dublin. A sense of sickening shock crept over us. We did not know what lay ahead. We spent the next few days breaking the news to family and friends and Googling "Foetal Acites". We began to realise that sadly there was a very big chance that our baby was going to die but I still clung onto the small chance that she would live.

We received a further appointment, and it was agreed that our baby had a condition called "Hydrops", which created Acites or a build-up of fluid which was preventing my little girl's lungs from forming. This condition is extremely rare, and sadly, our baby had to be the one who got it. Numerous consultants met together to review my scan, and all agreed that our baby would die. At this point in 2017, termination for medical reasons was not a legal option in Ireland, but even if it was, it was not right for us. We decided to let our little girl travel her own path. We wanted to try to make the most of the time we were to have with her.

An amniocenteses test was carried out to confirm her diagnosis and within a week, we were told that she had "Non-Immune Hydrops" alongside Downs Syndrome. I would have loved to take home a beautiful little girl with Downs Syndrome, but the experts felt that with her other complications of "Non-Immune Hydrops" that she would not live.

From that day forward, I locked myself away from the world. My husband and I went on long term sick leave from work and cocooned ourselves at home. I could not face the "when are you due" or "how are you feeling" questions from people who did not know about our baby's diagnosis. I could barely get through a morning without breaking down - every day waking with the fear that my baby's heartbeat had stopped. Emotions ranged from anger to grief to heartbreak but also to the joy of the little active lady still growing inside me, oblivious to it all.

My little girl was a fighter. Big kicks every morning let me know she was still there and so full of life. So, we began to try to treasure every one of these little moments and her little life. We decided to name her, Sadbh, an Irish derivative of Sue. As she was perfectly safe when she was part of me, we felt comfort from giving her my name. She loved music - play something to my belly and her little arms and legs would go crazy. She loved the sound of her two wild brothers too.

We took photographs together as a family and photographs of “bump”. She even had her own smell because I wore “Tommy Girl” every day of my pregnancy and to this day the smell of it brings me such warm memories. I do however have two regrets. One is that we should have made more memories, like recording her heartbeat, a belly mould or having a 3-d scan video completed as a momento. I did not at the time realise that one day these mementos would be all that we were left with of her. The only other regret I have is that I did not seek emotional support through either counselling or closed online support groups as I awaited her arrival.

Weekly scans continued. One week the scans would give us hope and the following week they would be dashed with dramatic increases in fluid in her little body. As she continued to grow, I had the heart-breaking task of shopping for the baby clothes she would eventually be buried in. That and packing my hospital bag in preparation to meet and lose my baby in the same day were the saddest things that I will ever have to do. My mind was constantly battling “How could this be happening to us?”. Life was just so unfair.

Our little fighter, against the odds, made it to 38.5 weeks and she decided at 6am on Saturday morning 11/11/17 that she was ready to be born. We asked my consultant for a team of surgeons and paediatricians to be in the delivery suite so that in case she might be born alive, they would be ready to work on her. But during delivery when I saw my consultant nod at them to leave, I knew the worst had happened. A very difficult labour had led to her little heart giving way just minutes before we got to meet her. Born sleeping at 12lb 4oz she was a lovely warm bundle of love. Sadly, she got cold so quickly. We got the opportunity to bring her home to meet our family and make some more precious memories and take photographs with our beautiful little girl.

From the 11/11/17, which happens to be Remembrance Day, my life has been split into life before and after Sadbh. As heart-breaking as it is to have my little girl in a grave rather than in our home, she still is a very active, live part of our family. Her name is mentioned every day and mementos of her life are scattered throughout our home. Deeds are constantly being done in her name and she has made me a more patient, empathetic, loving person.

Sadbh has also made me appreciate the small things so very much more. Once you have seen behind that curtain of life and death, you suddenly realise what is essentially important. I will never work full-time again, and for the first time in my 44 years, I am very content with my lot. I have also met a fabulous tribe of women in the bereaved Mammy’s community. Apart from my husband, a few close friends and family, these women honestly are the ones who got me through my grief. To know that someone else out there is thinking the exact crazy thoughts that you are and are having the same surreal experiences is the only thing that kept me sane throughout those dark early days.

These women are now firm friends for life and sad as it is, the unbreakable bond we share helps us all share with love, rather than sadness. **SC**

The 'firsts' of baby loss

By Catherine Travers

About the author: Catherine, originally from Ireland, lives in Perth, Western Australia with her husband Merv and her rainbow baby (a baby after loss), Lucy. After being diagnosed with severe endometriosis, Catherine endured numerous rounds of IVF before falling pregnant with her first son Benjamin. At 35 weeks pregnant she received the devastating news that Benjamin's heart had stopped beating. On 16 April 2017, her much longed for first son was born silently into this world. Catherine has a passion for creating awareness for stillbirth and pregnancy loss and blogs about her experiences at ***www.benjaminslight.com****.*

When I first found out that I was pregnant with my son, my life with him flashed in front of my eyes. Taking him home from the hospital, his first steps, his first words, his first day at school. It was all so exciting. The anticipation, the excitement, the hope. It had never crossed my mind that all of this would be snatched away from me and instead I would be left with another list of firsts, the 'firsts' of baby loss.

Benjamin died when I was 35 weeks pregnant. In an instant, my life crumbled into a million pieces. Everything that I knew as true was no longer. The boundless joy of growing a life had been replaced with the devastating reality that no parent wants to face – burying their child.

The first time I held you

I was so scared to hold my little Benjamin for the first time. I did not know what to expect. In my mind, I had built it up so much. To be honest I was not sure if I wanted to hold him. I feel awful saying that, but it was how I felt at the time. I remember the nurse rolling in the cot with Benjamin inside. When I first saw him, I let an unearthly howl out of me. The reality of everything that I had lost hit me like a tonne of bricks. There he was my perfect, gorgeous little boy. The nurse placed him in my arms and in that instant, everything felt ok. My baby boy was where he was supposed to be, in my arms. I soaked up every perfect little detail of him. In that instant, I was a proud Mummy like any other. Looking back now, holding him in those days before the funeral was the only time I felt at peace.

The first day home

I was dying to get home from the hospital. My naive self-thought I would feel better in the safety of my own home. But I had not thought of what it would be like walking out of the hospital doors with empty arms. I had not thought of the loneliness of returning to an empty house with an empty nursery. The first day home, a necessary but very painful first step to the rest of my life without my baby.

The first of many days without you

There are so many things to do when planning a funeral. Strangely it kept me busy and distracted. It was one of the few official things I did as Benjamin's Mummy. In the first few weeks, everyone rallied around us, there were endless flowers and cards and food. After the funeral ended and I held Benjamin for the very last time, everyone else went home and got on with their lives. But I was left with a gaping hole where my life should have been. The prospect of rebuilding everything and living without my child was overwhelming. I did not even know where to start.

The first smile

My first smile crept up on me out of nowhere. I was so shocked when it happened. It was the day after Benjamin's post-mortem results, and I felt like a weight had been lifted off me. As soon as it happened, horrible guilt came over me. How could I smile again after my son had died? Did it mean I was forgetting about him already? Of course, it did not. All it meant was that I had decided to try and live again. No moving on, just moving forward.

The first celebration

The first big celebration after Benjamin died was Christmas. We decided not to return to Ireland to celebrate it with family as it would just be too painful. Instead, we planned a very quiet one at home in Perth. No Christmas decorations, no expectations, no nothing. Just time and space to feel how we felt. Time to be ourselves as we missed our little boy terribly. The thing with celebrations now is that there will always be someone missing, always an empty place at the dinner table. For us, it was a case of survival that first Christmas.

The first day back at work

I was very lucky to have 10 months off after Benjamin died. When I eventually returned to work, I was extremely nervous but did feel like I was ready. By then I had already experienced the myriad of hurtful comments from a society that seems so scared of grief. I decided to take matters into my own hands and sent an email to my work colleagues outlining what was and was not helpful when talking with me. Whilst the first days and weeks back were undoubtedly difficult, the email did help me to navigate this huge step back into "normal" life.

The first birthday

Everything in the first year after Benjamin died was building up to this date – his first birthday. To say I was dreading it was an

understatement. The first birthday is the culmination of a year full of firsts, a year full of excitement, adventure, and exploring. But for us, it was a year full of everything that we had missed. A very stark reminder that we never got to take our baby home from the hospital. The weeks in the lead up were suffocating and painful, punctuated with crippling flashbacks of that fateful day when our world changed forever. But somehow on the day instead of being met with the usual debilitating grief, I had become so accustomed to, I was met with a strange sense of hope.
I felt light like a weight had been lifted. I felt love. A love so great that it shone brighter than anything else that day. I felt my little boy so close to me that I could swear he was there.

The first time you think that maybe, just maybe, everything will be ok

After Benjamin died, I thought that I would never be happy again. I thought that I would be destined to live a life of grief, sorrow, and longing. But somehow the first smile turned to the second smile and the first good day turned to the second.
Slowly I rebuilt my life and got comfortable with carrying the sadness of my great loss. Time did not heal but it allowed my love for Benjamin to overshadow the devastation of his loss. **CT**

Christmas – always missing, always there

By Lyndsey Lang

Lyndsey is Evalyn's Mummy. Writing has been a huge therapy for her since her daughter was stillborn on 8 November 2016 which was two weeks before her due date. Lyndsey started a blog **'After Evalyn' (https://afterevalyn.com/)** *to help reflect on her own grief experience and in October 2019 she was awarded* ***Author/Blogger of the year at The Butterfly Awards (https://finleysfootprints.com/the-butterfly-awards/)****. Lyndsey also studied Creative Writing and English at University. As well as having some of her early poetry, before Evalyn's passing, published in various anthologies. Her poems since Evalyn have also been used by leading baby loss charities as a tool to demonstrate grief and two of her loss poems have been published in another loss memoir. Lyndsey loves writing and talking about her daughter. She feels that it is so important to support others and raise awareness. No one should have to feel alone in grief as they navigate their journey and to whoever reads these words, she sends you her love.*

It is not always the most wonderful time of the year. For amongst the carols sung with glee and the lights that bounce off excited smiles, Christmas has a special talent for highlighting what it is a grieving heart misses the most.
Who **the grieving heart misses the most?**

For myself, who is my daughter. My baby who, had life not shown such cruelty, would have been four weeks old that very first Christmas. Instead, we faced it without her. And have seen four more Christmases since.

It is not an easy time of year when someone is missing from it. And the passing of years does not stop the ache in my heart when I turn the calendar over and am faced with another December. Because she is always there. And as she grows in my mind with the passing of years, there is more of her to miss. More of her to wish for. To long for.

I see her as a baby, unsure about the wrapping paper or the gift beneath it. I see her as a toddler, full of excitement and beginning to understand more and more. And I see her as the four-year-old she would have been the Christmas just gone, looking out of the window before bedtime in the hope she would catch a glimpse of Santa Claus.

I see her in the baubles we have collected for her, hanging on the tree. And as her collection grows, I feel the pain in my heart that the years are moving forward. She is both growing older and remaining forever young all at once. I see her in the empty chair at the Christmas table that should be hers and as dinner is served, I wonder what food on our plates she would have liked the most.

I wonder what her favourite carols would be and what her little voice would sound like singing them. I wonder what she would ask for on her Christmas list and what her handwriting would look like squiggled across the page. I think of what part she would have played in her nativity play. Whether she would have been reserved, like me, or eager for the main role.

There is so much wonder in Christmas. But for myself, I only wonder about her. For how can we not at a time of year that is aimed so much towards the excitement of the little people in our lives?

Christmas has changed for me. It is not what it once was and a part of me longs for the way Christmas felt without grief. But to live like that would mean to not know my daughter. And despite the heartache, she is still with us every Christmas. She finds ways to show us she is always there beside us. In my mind's eye. In her baubles. In the empty spaces I long to fill with her presence. For, although she is always missing, she is always there. And she always will be. **LL**

Talking to your child about their brother or sister who has passed

By Anne Marie Gillooley

About the author: Anne Marie Gillooley is a mother of two beautiful sons. Her first son Max was stillborn in January 2015. Flynn arrived pink and healthy 2.5 years later. Anne Marie constantly looks for the balance of joy and grief that comes from parenting after loss. Her blog ***l4stars.wordpress.com*** *is a collection of thoughts on stillbirth, pregnancy and parenting after loss, and infertility.*

After a normal healthy pregnancy, one Sunday evening at 41+4 I noticed that my baby had not moved for a few hours. With only the mildest of concern I headed into the hospital, expecting the reassurance of his thundering heartbeat, and perhaps even a queue skip ahead of the Monday morning inductions. Instead, there was only silence as our world changed forever.

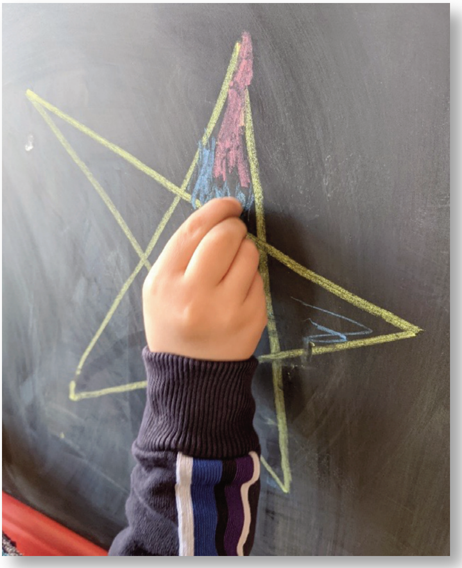
Even in those moments, I recall making a commitment to Max, the boy who made me a mother, that he would be forever loved and forever counted in our family. As he was delivered silently into the world, I was amazed by his beauty, by his perfection, by my overwhelming love for him.

We had hoped, as many do, to have a rainbow baby (a baby after loss) quickly. We knew that Max could never be replaced and that another baby would be an addition to our family. The desire to parent a living child, to feed them and hold them and watch them grow was incredibly powerful. We also knew that we would raise any other children we were blessed enough to have with the knowledge of their brother, and we would do everything in our power to make Max a positive and important part of their life.

Another child did not come as easily as we had first hoped, but, after a successful IVF cycle, our beautiful second son Flynn was born. His cries in that labour room, where we had known only silence, brought so much healing. From the moment Flynn was born we spoke of him as a little brother. Max's picture sat on a shelf in the delivery room, his teddy shared Flynn's first cradle. We bought rainbow onesies and vests announcing his status as a little brother. From when he was born, we pointed out Max's picture and talk to him about his big brother. We are not religious which can make the story a little more complex to tell, for now we have settled on telling him that Max lives amongst the stars, and that so long as we remember him, he is forever connected by our heart. One of my favourite books to read Flynn is called 'No Matter what'. The book ends simply but beautifully… *'Look at those stars, how they shine and glow, but some of them died a long time ago. Still, they shine in the evening skies. Love, like starlight, never dies.'*

Talking to a living child about their deceased sibling is not as straightforward as I might have once believed, and as he grows, I find myself struggling more to find this balance. One of my friends was telling me recently that she could not bear to tell her children about their cat passing away because she did not want to make them sad. I could not help but contrast the situation of their ability to avoid hard conversations with Flynn's exposure to grief, the innocence and normality of him saying goodnight to his big brother and 3 of his grandparents in the stars. I am sad for him that death and grief has walked alongside him from even before the moment of his conception.

I am also increasingly conscious of allowing him to feel like a unique individual, and not only a little brother or a 'Rainbow Baby'. As he approaches school age, I am less inclined to buy him the little brother t-shirts which might lead the other children to ask him questions or cause discomfort. I am increasingly conscious to make days like Christmas and Flynn's birthday feel like special days for him. We will always do something for Max to remember him, whether it is to light a candle, hang a stocking for him, donate to a charity in his name. I will always be aware of the absence of the 6-year-old who should be in the middle of all the fun, but I do not want Flynn to grow in an atmosphere of sadness, or to feel he has to live up to this image of a perfect sibling who never got to refuse his vegetables or have a tantrum in the supermarket.



It is my hope that Max will represent something positive to Flynn as he grows. A brother who he never met but who he associates with love. A special day in the middle of January where we bake a cake and eat a picnic at a special bench. A representation of the power and unconditional nature of a mother's love, a love which continues to embrace one son beyond this life, and which will envelop Flynn through whatever his life brings.

I often ask Flynn how much he thinks his Mamma loves him. He smiles with the cutest dimple and stretches his still-but-less chubby arms as wide as they can go to demonstrate the breadth of his mother's love.

Little does he know that there are not enough arms in the world to show the extent of that love. One boy that I adore more than all the world, and one that I love with more fire than all the stars.

What a lucky Mamma I am. **AMG**

Birthdays

By Linda Corcoran

About the author: My husband and I had been dating since I was 15. I always loved children and knew from a young age that I wanted to be a Mammy. I studied Childcare and Montessori in College and worked in a Creche since I was 20 years old. I adore children. We decided to start a family when we bought our house in 2005. Six years on and we were still childless and feeling very deflated. Our friends had started their families and we were attending christenings and birthday parties monthly. It really took its toll on us, and we decided to get some professional help. That is where our fertility journey started, and we finally became pregnant. We welcomed our son James into the world. We were besotted. Then we surprisingly had an unexpected pregnancy. I was going to have another baby. It was unbelievable, after doing fertility treatment and exclusively breastfeeding, it really was a miracle. We were overjoyed. Sadly however, at 38 weeks EmmaRose was stillborn.

Birthdays are a very special event in our house, no matter what age you are! EmmaRose was born on 23 July 2013, 1 year and 10 days after her big brother James, and as faith would have it, she was born 1 year and 1 day before her little brother Adam.

On EmmaRose's first birthday, I was in labour. I was induced the day before and fully expected for two of my children to share the same birthday, but Adam had other ideas and waited until the following day.

I always imagined what I would do on her first birthday. I reached out to other bereaved parents who had lost their baby who described what a hard, overwhelming day it was going to be not knowing how to spend the day, watching the clock and reliving events from that day the previous year – the day their baby died.

But for me it was different, I was exactly where I was that time the year previously and I felt so much fear that it was all going to go the same way again. It was very hard to juggle all the emotions, but I did not want to let the day pass without marking it for my baby girl. I asked her aunty to get some balloons and bring them and my older son James to EmmaRose's grave. My husband and I got a small cake in the hospital shop and placed a candle in it. I imagined with great sadness the party we would be having if she were here.

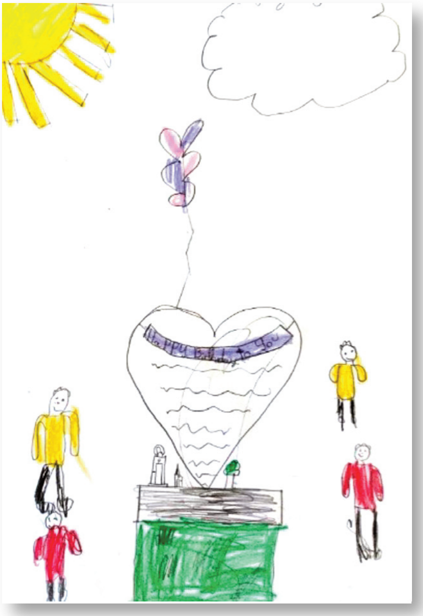
From that year on, we decided that we were going to celebrate her birthday. I always believe that EmmaRose is with us, that she is watching her family and would be laughing when we laugh. I decided that we would always have lots of fun, and that is exactly what we do.

On her second birthday, we went to the zoo. We had a lovely day. We had a picnic and a birthday cake, and I could feel her with us. On the way home, we got some balloons and went to visit her grave. As always, we wished that this was not our reality, but we hoped we made her happy and she enjoyed her special day.

When it was her fourth birthday, we went to Tayto Park; we had such a great time. As we were playing in the water area, a lady approached me and introduced herself. She recognised me from our Mammy Facebook group. She was there celebrating her daughter's 4th birthday. It was like a kick in the gut. I think it was just so unexpected that it threw me. Not that I would ever wish this on anyone, but it was a real look at what I should have had.

From then on, we decided to take a little staycation for her birthday. We always leave early on the morning of her birthday and have cake for breakfast and visit her grave on the way. We have been to some lovely places and always feel her close to us. My boys love telling people that it's their sisters' birthday and it makes me very proud. My favourite place we have been for her birthday is Youghal in County Cork. We went swimming, had dinner, and wrote her name in the sand as the sun set over the beach. It was beautiful.

In our sitting room we have three pictures of our children as babies - one of James, one of EmmaRose and one of Adam. With all their birthdays being so close together, we buy each one a big number balloon for their birthday. It is a special way of including EmmaRose in the celebrations that usually go on for the whole month of July.
LC



How Paddy and Joey, big brother, and little brother, remember their sister

By Georgina Culshaw

About the Author: Georgina is Mum to three children, two boys and a girl. On the 10th October 2010 (10/10/10) Georgina gave birth to her son Paddy. He was a healthy and happy baby born at 36 weeks. It had taken nearly a year to conceive Paddy and so when he was only 8 months old, they started trying again. Fast forward four years and after numerous fertility interventions she finally became pregnant again after IVF. Sadly, at nearly six months pregnant, Georgina was told that her baby had passed away. On the 17th April 2015 she brought beautiful little Molly into this world, sleeping and still. Molly means 'wished for child'. Suddenly life changed, it was never to be the same again. Georgina's rainbow baby, (a baby after loss) Joey, was born at 36 weeks on the 1st July 2016 happy and healthy.

There is not a week that goes by that Molly's brothers do not hear her name spoken in our house. They often refer to her as though she was here with us.

When Molly was born, Paddy was nearly 5 and was more aware of what was happening than we expected him to be. His brother or sister that he had longed for was nearly ready to make an appearance. The day we told him that she was gone, he hit out at me, and sobbed for what seemed like an eternity, as I cuddled him on his bed. He needed to know why. Why had this happened? It broke my heart as that was the very question, I was asking myself and I was a 38-year-old woman. How could this little boy ever possibly understand?

We made the decision to bring Paddy into the hospital to meet Molly. Just like we had planned, Molly had brought a present for him, and he opened his new Lego set while she lay in her cuddle cot beside him. He leaned over and thanked her for the present. He held her in his little arms and gently rubbed her head. He asked both her and us questions. So many questions. It was in that moment that I realized Molly would never be forgotten.

Paddy has a picture of himself holding Molly beside his bed. When his little friends would come over to play, they would ask about the very small baby in the picture with him. He would proudly say, that is my sister Molly, she died and is in heaven. With that they would go about playing their game.

Joey is now 5 and Paddy is 10 and they both talk about their sister often. I was recently at a hospital appointment with Joey, and I was asked how many children I had. I answered two and said that he had a big brother at home. Joey grabbed my arm and said, that is not right, I have a sister as well. I love those moments but at the same time they are the moments you feel guilty about. Why did I not say that I had three children?

Sibling rivalry transcends heaven and earth. We placed a small chocolate egg from their Easter baskets on Molly's grave this past Easter Sunday. Joey was very unhappy, even though he had lots of eggs he still wanted back the egg Molly had taken. There was no difference to him between Paddy taking an egg or Molly taking an egg. He was not about to let either of them away with it.

We encourage our boys to remember and include Molly as often as possible in our daily lives. Rainbows in the sky mean Molly is close. Feathers mean that she came to say "hi". Robins are special visitors when days need cheering up. On her birthday every year they release balloons and send them to heaven with special messages. Joey sleeps with "Molly bear" every night and she keeps him safe from the dark. Their Grandad recently died, and they were both happy to know that Molly would be waiting for him and that he would now mind her and show her love like he did for them. We have a special place in our garden for Molly and the boys love going to visit and play up at Molly's grave.
They help me clean it up and often bring her toys and presents from their playroom to leave on the grave for her. Nothing is strange for them when it comes to their sister Molly but over the years sadness has caught them out just like me. They both occasionally cry about her and ask why she cannot be here with us.

As a parent to three children but with only two with me, some days can be tough. You still have to remember to treat them all equally. It has taken me five years to realize that watching the boys remembering and including Molly is all that I need. I believe now that Molly will only be happy in heaven if I do not let her passing take over Joey and Paddy's world. My boys deserve to live a happy life and I am so very proud of them both for never forgetting their sister, Molly. **GC**

Our eternal butterfly

By Caroline and Martin Smith

About the authors: Caroline and Martin's son Stephen came silently into this world on 20 October 2015 at 20 weeks plus 2 days gestation. Stephen was 420g of perfection and he was the image of his daddy. Caroline and Martin also have two older girls, Amy who is 13 and Sammy who is 11. They also welcomed their rainbow baby (a baby after loss), Olivia, 4 years ago.

A planned pregnancy

Due to a medical condition, all my pregnancies were planned to ensure both myself the baby had the best of care. It took a while to get pregnant on Stephen, but we were all thrilled when we saw that magical two lines on the pregnancy test.
Amy and Sammy very much wanted a baby brother. Everything was going to plan with no complications until 20 October. Stephen died because of an e-coli infection.
Martin calls him his superhero because the doctors were baffled as to why I was able to sit up and talk; they told him that he should be planning two funerals because of the amount of infection markers in my body.

What Stephen's birth means to our family

From the moment he was born, we adored him. He had the longest fingers and he had the biggest of feet. I was in awe of the length of his fingers. He had a cute button nose and the perfect little mouth. When I was discharged from the hospital, I still needed and wanted to see him as much as I could before his cremation, so Martin and I agreed that we would visit him in the hospital Chapel of Rest as much as we could. We brought Amy and Sammy with us, and I will never forget the first time I saw them both hold him. The pride in their eyes and the biggest grin on their faces. They adored him and there was no element of fear or uncertainty about seeing him. He was their baby brother and they wanted to see and hold him.
He was our eternal butterfly.

Remembering our baby

It is not hard to include Stephen in our lives. It came naturally and thankfully we have the support of family and friends who respect this. Every year, we celebrate his birthday with cake and candles. We add Stephen's name or add a little butterfly to all cards that we send at Christmas or on birthdays. When it comes to Christmas and writing letters to Santa, the girls spend ages looking through toy catalogues trying to decide what he would be into, and they include that in their letters. We have two shelves in our living room, which holds all the little bits we have received from family and friends to remember Stephen, pictures that Amy and Sammy have coloured in as well as his little urn and toys from Santa.

For Stephen’s first birthday away from home, Martin ordered a “grow your own” butterfly kit. Coincidentally we received five caterpillars which I felt was so special as when we ordered there was no guarantee of how many caterpillars we would receive. Just before Stephens first birthday, we released the butterflies with our families. One butterfly hung around for a few hours, no doubt he wanted to see all the fuss and the cake.

As we approached Stephen’s 1st birthday, I found out I was pregnant with our rainbow baby. When she was born in April 2017, I had Stephen’s little teddy bear, “Stephen Bear” in my hand. “Stephen Bear” sat in the crib with her until she came home. Now that she is four, she is well aware of who her big brother is. When she sees a butterfly, she always says ‘There is Stephen saying “hello”’.

Why it is important to remember Stephen

I love all my children whether I can hold them in my arms or not. I hold all of them in my heart, always. I am a firm believer that baby loss should not be a taboo subject. I am not ashamed of my son. I am his mum, and I am honoured to have that role. I talk about and share pictures of all my children. Unfortunately, Stephen’s pictures will always remain the same. Stephen is not visible on our family tree because he was born before 24 weeks gestation and because he weighed less than 500g, the Irish State does not recognise him as being stillborn. He did not meet the criteria to receive a stillbirth certificate. Because of this, Martin and I have been lobbying politicians for a change to the Stillbirth Registration Act of 1994, which would see babies born outside of the criteria for stillbirth, receive an official certificate from the Irish State to acknowledge their existence. We will continue lobbying until we see change. The fact remains that I gave birth to Stephen. He was stillborn but the important thing is, he was ‘still born’. **C&MS**

Reminders of what we are missing

By Claire O'Callaghan

About the author: Claire is mother to two children. Her son Sean, who was her firstborn, was stillborn at 39+3 weeks. Claire went on to have a "rainbow" baby (a baby after loss), a daughter who was born 14 months after Sean. She is now 2-and-a-half. Her daughter was unexpectedly born slightly early at 36+5 weeks as her placenta had started to fail, just like Sean's had. This means that any future babies that Claire has must be delivered at 36 weeks. After her daughter was born, Claire attended a mental health doctor to help her with the emotions and thoughts she was having after Sean's passing and she was diagnosed with delayed grief reaction. After a lot of counselling, Claire has learnt it is okay to show emotion, and that she does not have to put on the mask of 'I'm fine' as this can be exhausting.

Milestones and special events

At each milestone our daughter reaches, we also wonder would Sean have done that or what would he have liked to do. Special events such as birthdays, Christmas and first day of pre-school are all reminders that Sean is not here.

At Halloween, outfits in the shops are a reminder that we will never see our little boy dress up in a superhero outfit and pretend he can fly or jump high buildings.

Christmas reminds us that there will always be one empty stocking on the fireplace. It is so hard to know that we will never see one of our children getting excited over Santa and opening his presents. Our hearts ache when we see one, and not two, little faces walking down the stairs in their Christmas pyjamas to see what Santa has left by the fireplace.

At all these celebrations, when a family photograph is being taken, we are reminded that one little boy is missing from the photograph.

Times of the year

Winter used to be my favourite time of year, particularly Christmas - with the tree in the window, the fairy lights glowing and the fire alight. However, since Sean passed away, I am in a daze for most of December and I do the decorations because it is what you do.

Now I instead enjoy Spring because to me, it represents new beginnings and in Spring, we found out we were expecting another baby. While we will always grieve for Sean, finding out that we were expecting again, brought a smile back to our faces and we began to learn how to continue to include Sean in our lives.

Coping with our loss

Every year, on his birthday, we celebrate Sean with our families by hosting a bubble release at the time he was born. We also get something special for our garden in his memory, and his little sister gets a present and we go out for the day.

At family occasions be it christenings, communions, confirmations, or birthdays, we include Sean with a little teddy bear, who we have named Ted. Ted is included in family photographs, and everyone knows who Ted is and how special he is to us.

At Christmastime, we have decorations on our tree especially for Sean. His little sister also gets a special gift from Sean to her and we light Sean's special candle.

On any cards that we write, we include Sean's name as he is part of our family. It is hard however, when other's do not include Sean on the card that we receive.

We always miss Sean, and he is always in our hearts. Sean made us a Mammy and a Daddy on the 28 August 2017, and we will always be a family of four. We wish he were here to play with his little sister but instead he is watching over her and protecting her. **CO'C**

How I managed to cope with the loss of our daughter

By Nigel Black

About the author: Nigel is Dad to Sophie. Sadly, Sophie was stillborn as a result of Group B strep. Nigel talks about how he works as a funeral director and how he managed to return to this work after Sophie's passing. He also tells us about how the supports he received from his family and friends got him through his immense grief.

Monday 12th August 2013 is a day I will never forget as long as I live. The pain and heartache myself and my wife endured that day will never be forgotten. In a split second what was meant to be a beautiful and joyful day turned out to be the darkest day of our lives.

In the aftermath of our little girl's stillbirth, the days and hours and weeks ahead were pure torture. Everywhere I turned was a reminder of what we had lost and in particular, the items we had purchased for Sophie Rose's arrival were painful to look at.

I asked myself on numerous occasions how was I going to cope with Sophie's passing and come out on the other side. I had to admit to myself that I would never accept the fact that she died but I would have to learn to cope with it.

In my job as a Funeral Director, I could not see myself going back to work and coping with death, but after time off and reflecting on things, I did go back, and I now am able to understand exactly how bereaved people are feeling and the emotions they are going through.

If it weren't for my wife and our good friends and family, I would never have coped with our loss. What helped me cope with the loss was talking about Sophie as if she were alive, and when other family members mentioned her name, it brought, and still does bring, a smile to my face that she existed even though her life was short and brief, she was and still is a member of our family.

We also received supports from baby loss organisations, and we soon realised that we were not the only ones going through the loss of their child.

We held a fundraising night in memory of our Sophie, and we raised a wonderful €5,000 which was used to purchase and donate two cuddle cots (which are cooling units that are placed into a Moses basket). One cuddle cot was donated to Holles Street National Maternity Hospital in Dublin, and another was donated as a community cot so that bereaved parents could use it to bring their baby home for a short while. Honouring Sophie's memory in this way helped us immensely in our grief. **NB**


Sister
Mam
Me
Dad

When things go wrong or unexpected in pregnancy

By Siobhán Whelan

About the author: Siobhan has three children. She also had two first trimester miscarriages. Siobhan's daughters are Susie and Ella. Sadly, their baby brother Conor, died unexpectedly from complications of undiagnosed type 2 vasa praevia when he was just seventeen and a half hours old. Following Conor's death, Siobhan set up ***VP Ireland (@vasapraeviasupport&awarenessireland)*** *which aims to increase awareness about equality of care for all mums and babies and to advocate for improvements in screening during pregnancy.*

Siobhan through her work with VP Ireland, has successfully campaigned to ensure that there is equal access to the anomaly scan in all 19 maternity units throughout Ireland and she continues to advocate for the development of policies and guidelines in relation to screening during pregnancy

Learning the hard way about baby loss

It was not until I had two miscarriages in close succession that I found out that 1:4 pregnancies end in miscarriage. Before that I was blissfully unaware. They were big losses for us and rocked my previous oblivious ignorance to pregnancy loss. I did not intend getting pregnant so soon after our second miscarriage, but I did. I was scared of another loss and the impact it would have on our wellbeing. But as this pregnancy progressed along nicely, I dared to hope again and to dream as the weeks passed. Initially, our only concern was the reoccurrence of a Group B Strep infection, that I had in all my previous pregnancies, but I was fortunate to be diagnosed and would receive the treatment needed. Sadly, no one ever told us about vasa praevia or its risk factors and unfortunately, I had four of the risk factors. There were missed opportunities to diagnose us and save Conor's life by an elective caesarean section.

Conor's time with us here

When Conor was born, I was not awake, and I was unaware of his deteriorating condition. My life was hanging in the balance too, from major blood loss and injury following his delivery. His poor Daddy was all alone. He was in complete desolation until my sister arrived to help him make sense of the dire situation that we were all in and to help with the decisions needing to be made for our little man who urgently needed transfer to a Neonatal Intensive Care Unit in Dublin. But all the odds were stacked against us sadly. All too little, too late and a happy outcome was not to be.

The only comforting consolation for us has been that Conor knew nothing but love from those who helped care for him in his short life, with some staff going way beyond their call of duty for our family. Gifting me and his beautiful big sisters the chance to meet our handsome little man while he was alive gave us the chance to spend time together and make precious memories. We will always be eternally grateful for the commitment of healthcare staff to ensure that we were all together when Conor needed us most and we needed each other. As a small gesture of thanks, we gifted some blankets to our local Special Care Baby Unit in memory of Conor.

What has helped me to carry on

I threw myself into advocacy for better, safer maternity services after losing Conor and going through my own near-death experience. I am his voice now. Advocacy work has been my lifebuoy, and quite possibly saved my sanity at times. I have met other wonderful parents with similar losses and aims on this journey, whom I consider good friends now. I like to think we help carry each other when one's spark goes dim, because though some good changes have happened through a lot of combined efforts, it is a most painful and frustratingly slow process to see the changes needed happen.

We have endured numerous difficult investigative processes following Conor's devastating passing and not all questions have been answered. This has been a huge barrier in our grieving and healing ability. We can only hope that the policies that VP Ireland advocates on will offer an easier pathway for others.

Where has time gone to?

It is hard to believe we have just marked our precious little man's 7th birthday and anniversary in May. I do not know where the years have gone too.
Much of it is a blur to be honest.
Everyone grieves differently, even in the same family. It has been a bumpy road indeed. Conor's death has impacted our extended family and close friends more than I ever realised before. With many doing lovely deeds still today to acknowledge our beautiful boy's existence. I do not know how we would have survived without the support from them and the wonderful supports of baby loss organisations. We are still here somehow - still standing. As a family and community collective, we ran some fundraisers in Conor's memory for the charities closest to our hearts and that has helped us on our journey. Doing this, has brought us great joy.

We miss Conor as much now as we did when he died 7 years ago. All the hopes and dreams we had for this little man were taken away in a heartbeat. Such losses leave their mark. I imagine often what and who he would be today - this seven-year-old boy. We remember, honour, and include Conor at all times. We count him in. We celebrate his birthday with a cake and candles and sing to him. Even Santa remembers our little boy! I light his candle here in the kitchen every day. I need to feel close to him always. Robins bring me much comfort when I see them – I feel that they give me a close connection to Conor. Keeping his memory alive now is all we can do.
A mantra that helps keep me going is from a quote I saw some time back: *'When you feel like giving up, remember to walk for the steps your child will never take.'* **SW**

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under Section 39 of the Charities Act 2009
RCN 20100100, CHY21984.