



## Dedication

Dedicated to our babies *Mia, Grace, Joshua* and *Charlie* and all the babies remembered in this booklet - our missing pieces who have inspired us to create and contribute to this loss memoir in their honour.

Love - *Niamh, Bernadette* and *Sharon*



## Introduction

This loss memoir hopes to allow you to experience the journey of others who have lost a baby or babies in a multiple pregnancy. If you are a bereaved parent, these experiences might be familiar to you and will hopefully offer you some comfort.

# Contents

*Seeing it from Both Sides* ..... Erin Harrison-Smith ..... 4

*Losing my Twin Daughter nearly 30 years ago* ..... Judy Carmody ..... 7

*Reminders of What We Are Missing* ..... Niamh Connolly-Coyne ..... 9

*Christmastime* ..... Bernadette Tonge ..... 12

*Remembering my Babies* ..... Sharon Darke ..... 15

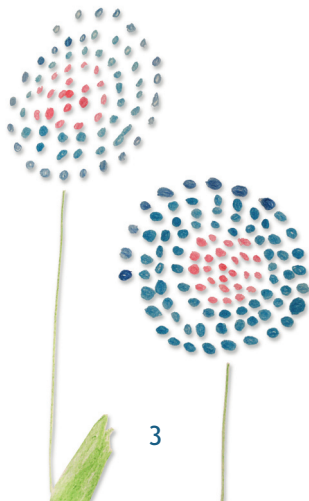
*Birthdays* ..... Barbara Carson ..... 18

*Getting a Medical Diagnosis for One of my Twin Girls* ..... Mel Bentley ..... 20

*Talking to my Surviving Twin about his Twin Brother* ..... Allison King ..... 23

*Firsts* ..... Ellie Curran ..... 26

*How my Surviving Twin Includes his Twin Brother* ..... Elizabeth Flynn ..... 30



# Seeing it from Both Sides

## *Erin Harrison-Smith*

*About the author: Erin Harrison-Smith is a surviving twin. Her twin sister Jessica died around the time of her birth. Erin has grown up knowing what it is like to live her life without her twin sister. She also understands what it is like to be the mother of a surviving twin as sadly one of her twin boys passed away at 24 weeks. Erin understands it from both sides.*

## Being a Surviving Twin

I am a surviving twin myself. My parents never officially told me that I am a surviving twin as they talked about my identical twin sister Jessica from when I was very young. She was a part of my everyday life - part of my core. We were identical twin sisters and identical souls. The one and the same. I remember when I was older, sometimes my mother would ask me when I liked something, if I thought Jessica would have liked it too.

When I was younger, death was quite foreign to me. I did not properly understand it. I knew that there should be *another me*, but there was not. As I understood it, Jessica was in my Mummy's tummy and umbilical cord had wrapped around her neck and she died. My mother then had to go to bed in hospital and was not allowed to get up for months, until I was born. I am sure my mother mourned so much. She told me she disliked being in hospital and disliked being separated from her first daughter who was only three years old at the time.

As I grew up, and I became very shy. I would miss my twin sister fiercely. But I felt that she was with me all the time no matter what. She was a steady presence in my life.

## Becoming Pregnant with Twins

My partner and I had been together eight years when we became pregnant. It was after a few days of feeling sick that I went to the doctor. They decided to do a pregnancy test. I had done dozens of these over the years, all to the same negative result. When she told me it was positive, I was so shocked. We told our parents, who were over the moon. My mother even joked it could be twins.

When I went for my first ultrasound the sonographer turned the screen to me and explained that I was expecting identical twins. She showed me two little black spots as I wept with awe. It just so happened that the sonographer was a twin as well, with dozens of sets of twins in her family. These were going to be the twins that my family were owed.

## Losing One of our Twin Boys

We were cautiously optimistic about twins due to the rate of vanishing twin syndrome, but I made it to the second trimester and relaxed. However, at week 15, I started to get a horrible pain in my side. A week later I could barely function. I ended up having another ultrasound, which revealed that we were having boys but there was a difference in size between them. Twin B was very small and stopped moving completely. I got a diagnosis of Twin-to-Twin Transfusion Syndrome. The doctor so gently told me the chances of losing one, even both twins. For the first time, I was properly fearful of history repeating itself.

We were then booked in for laser treatment to divide the placenta. Due to the risk of the surgery, we named the boys. Twin A became Hershel, and Twin B Finnley. The procedure was a success, and the next day Finnley was already moving again. It really looked like we were going to have twins. I allowed myself to get excited. We signed all our Christmas cards from the boys.

A few days later, we experienced another recurrence of Twin-to-Twin Transfusion Syndrome. It sunk in instantly, as though I knew it had been our fate all along. It felt like a family curse, inescapable, and I had been delusional to think otherwise.

Finnley passed on the morning of 22 January at 24 weeks. At 37 weeks exactly, we welcomed Hershel into the world. He had gone into distress as the cord had wrapped itself around his neck.

They told me I could meet Hershel for just a moment before he went to the Neonatal Intensive Care Unit and I put him on my chest. He was breathing, struggling, but surviving. Without speaking, I told him we are the same, I survived too, and we will both be okay.

## Knowing Both Sides

I have grown up knowing what it is like to be a surviving twin and I will know how to support Hershel, my surviving twin, as he grows up. But I also now know what it must have been like for my mother to lose one of her twins, and I understand it from a mother's perspective as well.

I do think a lot about how I should navigate the journey ahead with Hershel, especially in finding the right balance between celebrating his life and grieving for his twin brother Finnley. There is of course no one size fits all answer. I will let Hershel lead the way in how he wants to mourn and honour his twin brother. From my experience, acknowledgement of his twin and his emotions is vital. My twin sister's photographs, ultrasounds, and ink prints were kept locked away,

and I would secretly go through them at every opportunity. It made her feel secret, and after early childhood, she was only mentioned on rare occasions, despite her being constantly on my mind. I am sure my parents thought of her too, every day.

I plan to always keep Finnley's urn and pictures around the house. I have found even saying his name aloud everyday has been powerful. Perhaps Hershel, who is still quite young, will feel the same. I think the visual reminders of things like photographs also serve as an invitation or opportunity to discuss him.

Hopefully, our grief will be something that we will weather together, rather than it being an individual weight.



# Losing my Twin Daughter nearly 30 years ago

*Judy Carmody*

*About the author: Nearly 30 years ago, after fertility treatment, Judy was pregnant with twins Niamh and Shane. Her twins were born a little more than eight weeks early. Niamh had a difficult delivery. Her lungs were not fully developed. This meant that she was on a respirator immediately after her birth. On day 2 of her life, she had several brain haemorrhages and sadly she passed away. Judy wants to help more recently bereaved parents along their journey by sharing her story and her experiences of life after loss.*

## Supports that were Available

It is nearly 30 years since my twin daughter and son, Niamh and Shane were born. Sadly, Niamh passed away due to complications at birth. Back then, baby loss organisations were very new, and the hospital staff did not know who to refer me to for support. As a result, I did not know where to turn after I left the hospital. That said, at the time, the hospital staff that we met were brilliant. They encouraged us to take photographs of Niamh as well as keeping a lock of her hair. These keepsakes have become our most treasured possessions. I am also glad that we could bury Niamh in our family grave not far from our home. This was and continues to be very important to me.

## Other Supports that would have Helped

In the 1990s, losing a baby was even more taboo than it is today. It was something that others expected that “you just got over” and did not talk about. This was very difficult for me as I felt alone in grieving for Niamh. I would have really benefitted from a support group of other parents who were coping with a similar loss as well as some counselling. Unfortunately, that was not available as a service at the time like it is now through baby loss support organisations.

## Supports Today

Nowadays, while social media can be blamed for a lot, a key benefit of social media is that it allows others to share experiences, especially when it comes to baby loss. I recently joined some closed Facebook groups of parents who have experienced a loss in a multiple pregnancy. It is consoling to read other parents’ stories and to relate to them. Talking to and linking in with other bereaved parents who have lost a twin, has given me the strength to speak openly about

Niamh to others outside my family without feeling uncomfortable. I always wanted to share my experience of having had twins and meeting other bereaved parents has given me the strength to do so. I remember Niamh every day and she is a big part of me. Sometimes my mind wanders, and I think about what it would have been like to have a daughter. I find myself trying to picture her and what she might have looked like. I want to celebrate and include her but up until now I felt that society was not ready to hear our story.

I am so thankful that times have changed and there is more support available for those who experience loss in a multiple pregnancy. I know first-hand how difficult it is to find a balance between the joy of one child and the loss of another. I am glad that there is now a more heightened level of awareness which is essential and beneficial to parents.

## Advice to Recently Bereaved Parents

My advice to newly bereaved parents is to get involved in a support group whether that be face-to-face or online via social media. Reach out and get the support that you need.



# Reminders of What We Are Missing

## *Niamh Connolly-Coyne*

*About the author: Niamh is mother to three daughters. One of her twin daughters sadly passed away a few weeks before she was born because of a heart condition called hypoplastic left heart syndrome. Quite soon after her daughter's passing, Niamh quickly realised that there were very limited resources for bereaved parents in Ireland in relation to losing one or both twins. She therefore decided to volunteer her time to ensure that these resources were made available to bereaved parents and also to advocate on issues relating to baby loss in a multiple pregnancy.*

*Niamh also set up **Peas in a Pod - Loss in a Multiple Pregnancy**, @peasinapodireland and is a part of the writing team for **Still Standing Magazine** at [https://stillstandingmag.com/author/n\\_connolly/](https://stillstandingmag.com/author/n_connolly/)*

## Milestones

First day of pre-school and school, birthdays or celebrations and filling in forms that ask you how many children you have, are all reminders of what we are missing out on. For each milestone, I wonder what life would be like if my daughter's twin sister, Mia, was still here.

I was so excited for Emma, Mia's surviving twin, on her first day of school. She was ready for it. It became a day, where I both laughed and cried. I celebrated all that was and grieved for what should have been. My heart jumped for joy for our darling Emma but ached so hard for Mia not being there with her twin sister walking into their new classroom together.

With every significant occasion for Emma, our pride and joy is tinged with sadness that Mia is not here sharing the same experiences. I have come to realise that even at the happiest of occasions, both joy and sadness co-exist together. We celebrate achievements with Emma while we mourn Mia's absence.

## Special Events and Occasions

Christmas, New Years, Easter and Halloween are occasions that can resurrect our grief. The first ones were particularly hard. We love to celebrate and enjoy these occasions, but each is a reminder of what could have been.

Halloween reminds us that we will never get the opportunity to dress our twin girls in cute identical outfits and go trick or treating around our neighbourhood. I imagine how each door we would have knocked on, would have neighbours telling us how adorable our twin girls are in their matching outfits.

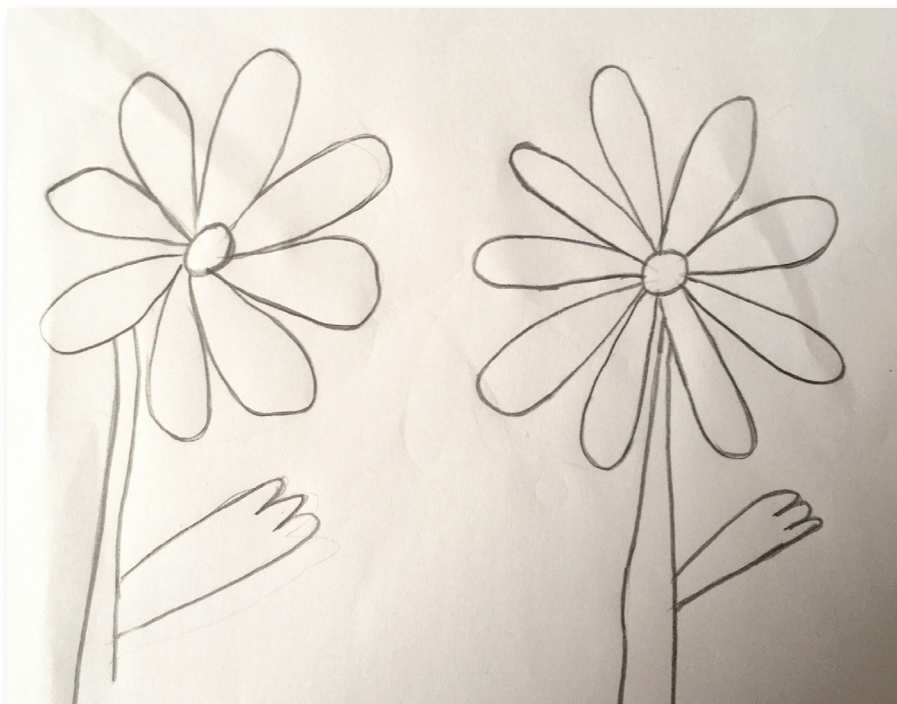
Christmas reminds us that one little girl is not here to open her presents from Santa Claus. Her toys remain unopened until I open them with Emma, on Mia's behalf.

Mother's Day and Father's Day are bittersweet too. Although we celebrate these days knowing we are parents to three daughters, we long that Mia was here with us.

Our twins' birthday brings about the challenge of celebrating one child and grieving for another at the same time on their birthday.

## The Seasons

I love the different seasons of Spring, Summer, Autumn and Winter and the new and beautiful things in nature that each season brings. Late Spring and early Summer bring, for me, particularly strong reminders of Mia. The vibrant yellow daffodils that spring up in March and April, remind me of the time when we heard that Mia had not survived, and we were awaiting her delivery and her upcoming funeral. I have a love/hate relationship with daffodils. They bring about both happiness and sadness when I see their arrival in our gardens and along the motorway.



## Coping with Reminders

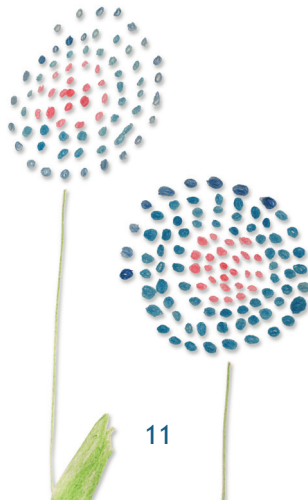
At each milestone and special event, we will celebrate with our family and friends and be thankful for all that we have. But we also think about what should have been and often see reminders of our precious twin daughter.

But all these reminders also give us an opportunity to include and remember Mia as part of our family. It eases our loss by including Mia at every milestone and in every special event. We try to focus on ways that Mia is still here with us just in a different way. Over the years, I have collected a lot of mementoes such as bears, trinkets, jewellery, and candles in Mia's memory. They are reminders of her and help us to include her.

At Christmastime, we include Mia by lighting a candle after mass early Christmas morning and we decorate our Christmas tree from top to toe in angel and butterfly decorations. For Halloween, we include her by making a flower arrangement using pumpkins and colourful autumn leaves. At Easter, we plant beautiful shrubs in our memorial garden at our home after the Winter months. On our twin's birthday, we add some little butterflies onto the cake as a reminder that she is always with us.

We think of Mia every day and will do so for the rest of our lives. She is a big part of our family story. I know that a piece of our hearts will remain with Mia.

We will always wish she were here with her sisters.



# Christmastime

## *Bernadette Tonge*

*About the author: Bernadette Tonge is mother to three daughters Mary-Kate and identical twins Susie and Grace. At 30 weeks pregnant, due to acute Twin-to-Twin Transfusion Syndrome (TTTS), Grace was stillborn. Bernadette loves to talk and write about Grace and enjoys spreading awareness about loss in a multiple pregnancy. She also volunteers her time to support others who have experienced stillbirth and prematurity.*

## The Season of Christmas

Christmastime is probably the season that I find most challenging when it comes to mixed emotions. There is the joy of seeing both Grace's older sister, Mary-Kate and her identical twin sister, Susie, open their presents on Christmas morning coupled with the sadness of knowing that Grace is not here to open hers with them. Sadly, our beautiful Grace was born sleeping when I was 30 weeks pregnant.

Christmastime reminds us of the happiness, joy, and surprise that we experienced when we found out we were expecting twins at our first scan. To say we were shocked when we saw two babies on the screen is an understatement. We were 100 per cent overwhelmed, shocked and speechless. Secretly, I was so scared, but I was also so happy to have been given this surprise gift and the hope of growing our family from three to five.

## Family Traditions

Christmas is a time to start family traditions and so the following Christmas after Grace's passing, we got two new stockings to hang on the mantelpiece - one for her and one her twin sister. Now each year we fill the girls three stockings full of presents. While Mary-Kate and Susie write their list to Santa Claus, we also write a letter for Grace and her stocking is always full of sweets and an extra surprise, which both her sisters get to enjoy.

We enjoy visiting Grace's grave at Christmas time, or as her sisters now call it, Grace's garden. It is sad that instead of playing with Grace and watching her grow, we try to find different ways to remember her. At each occasion, birthdays, Mother's Day, Father's Day, Easter, we get a new plant in her garden and her sisters enjoy watering them and making Grace's garden look pretty.

## Our 'Grace' Tree

When we decorate our Christmas tree, we hang lots of beautiful angels, butterflies, and special ornaments on it, which are personalised especially for Grace. The first personalised Christmas decoration we received was from another twin Mom who sadly lost one of her twin boys. This was such a nice touch and started my love of personalised ornaments for Grace. I love to see Mary-Kate and Susie remember the importance of these decorations to us. After our first Christmas, I did not have the heart to put these decorations away. Instead, we have a decorative corner in the living room which we call our 'Grace Tree'. It is full of fairy lights and angel decorations all year round.

## Christmas Songs

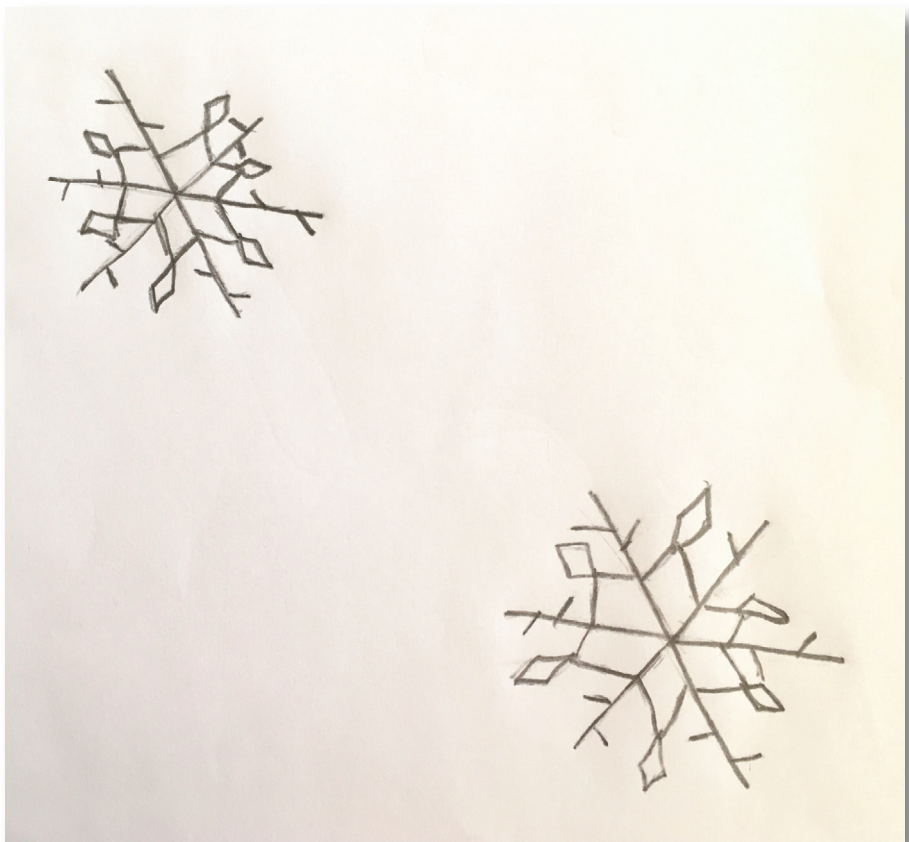
I always love to hear our local choir sing at Christmas Eve mass and listen to Christmas carol singers. I remember being caught off guard when I heard the hymn 'Amazing Grace' being sung. It was the first time I heard it after losing Grace. I was shaken by the experience and my whole body ached as I cried. It was like a release button that had been pressed. I was spending so much energy trying to go around my everyday life, working, looking after the girls, and trying to stay positive. Then in a moment of calm and hearing this beautiful hymn, I literally fell to pieces. I kept asking "why did we have to lose Grace? Why couldn't both our twin girls survive?" As my husband held me tight throughout the song, we silently showed that we cannot always be strong and hide our feelings. We cried and smiled at each other knowing that we together will always hold Grace in our hearts, and she will never be forgotten.

## Our New Normal

I have wondered if I will ever return to 'normal' and be able to fully enjoy Christmas again. But I have come to realise that we have moved onto a 'new normal'. One of the hardest aspects of losing our daughter has been dealing with other people's reactions to our loss - awkwardness, pity, shock, and the sense that we should not talk and grieve for Grace even at Christmas time. Others want us to just be happy that we have her surviving twin Susie. And of course, we are so grateful for our Susie Sunshine, which goes without saying. I just wish that is was easier to talk about Grace safe in the knowledge that she is treated like our other daughters.

What I find hard in trying to act 'normal' is that I also feel guilty that I continue to live a life and be happy all the while missing a piece of my heart, missing a piece of myself. I know that Grace would not want me to feel like this. She would want me to be happy and mind her sisters and Dad.

I will still talk about Grace, keep her pictures up, and support other families who have lost their baby in memory of her. I will continue to talk about her to her twin sister, tell her big sister all about her, and tell strangers that she existed when they ask how many children I have. Death does not erase a life, nor does it erase our love. I will always want to honour Grace's memory. Grace changed my life. She matters and lives on through her energetic twin Susie. And so, I pick myself up and try my best to focus on all the positives in our lives - and there are lots including my loving husband, beautiful daughters, and supportive family and friends. Grace will always be in our hearts and is with us everywhere especially on occasions like Christmas. Her Grandma Mary is minding her for us in heaven and she is looking out for her sisters who have a very special guardian angel in our Amazing Grace.



# Remembering my Babies

*Sharon Darke*

*About the author: Sharon Darke's identical twin boys, Charlie and Joshua were born at 26 weeks in 1999. Charlie was 1lb 12 and lived for 7 days and Joshua was 1lb 10 and lived for 13 days. Sharon has some lovely memories from their time on the Neonatal Intensive Care Unit. They were her first babies, and they would be 21 years old this year. Sharon also has a daughter Jessica who is 20 and a son, Samuel who is 18.*

*Sharon is the bereavement group coordinator for the charity **Twins Trust** in the UK, who gave her the most amazing support in the early days <https://twinstrust.org/bereavement.html>. She also writes a blog which you can find at [sharondarke.wordpress.com](http://sharondarke.wordpress.com).*

## Keeping Their Memory Alive

For me, it has always been so important to keep my twins Charlie and Joshua's memory alive. I remember so clearly having a conversation with the head teacher when I went back to the school that I taught in, two months after they died, explaining that I never want people to forget about my twins and her promising that they would not. I found it easier as more people asked about them, especially in the first few months.

## Writing About My Babies

One thing that I did straight away, which I found helpful was to write down Charlie and Joshua's story. I then added it to my photograph albums of the boys along with all the thank you letters that we wrote to the hospital staff. It is lovely to look through. We were also so lucky to be given gorgeous memory boxes, which Jess and Samuel, my two children that I had after the twins, would often ask to look through. I also bought some jewellery that I had engraved, and my husband bought me a ring with their names and two stars on it, for our first Christmas without them.

## Occasions are Opportunities to Remember

It is probably times such as Christmas, Mother's Day, Halloween, birthdays, and other special occasions that are the most difficult. However, I view these events as an opportunity and a way to do something special to remember. On these special occasions we always light a candle during our meal. It is my way of including them even though they are not physically present. On Mother's Day, we always take some flowers to the cemetery and try to do something together as a family.

Dominic, my husband, is especially good at buying me a card from them both. Christmas was very difficult the first year. We made it more bearable by giving photographs of the twins to close family.

It is on their birthday/anniversary on September 13th that we dedicate the day to them. We have such special memories of their birthday over the years. We have enjoyed having a tea party, making a birthday cake, fundraising for a 10-mile walk on their 10th birthday, 15k obstacle run for their 15th birthday, 18 things for 18 days for their 18th including an 18-mile run, a barge trip for the day with family, visiting the cemetery, picnics and special meals.

I am so lucky that I always receive birthday and “*Thinking of you*” messages and cards from my lovely family and friends. This means so much.

They are always remembered.

## Family Occasions

There have also been many family occasions over the years where we remember Charlie and Joshua including my Mum and Dad’s Ruby Wedding party, family weddings as well as our own occasions. We used the top layer of our wedding cakes as our Christening cake, as tradition we kept the cake for Charlie and Joshua and had two little stars on it and my mum made Jess her own Christening cake. I have been so touched by how others remember our boys which have brought ‘happy’ tears.

## Siblings Remembering Their Brothers

We have brought Jess and Samuel up to always talk about their older twin brothers. They are and always have been happy to chat about them. They would regularly show their friends the photographs of Charlie and Joshua. I loved to see Charlie and Joshua’s names in their schoolbooks too, particularly when they did a family tree. We always encouraged Jess and Samuel to make suggestions about what we could do for their birthday each year. One year, Samuel wanted to release football balloons for them at the cemetery. He was so pleased watching them float up to the sky as he wanted Charlie and Joshua to have them to play with. Another year, Jess asked to take a photograph of her brothers to school which was received so well by her lovely teacher. They have been involved in the fundraising and supported me as I completed the London marathon. I recall how I wore lilac ribbons all over my vest which included the names of babies who sadly had also died. It was so good to see Jess and Samuel at mile 19 when I was struggling. They both ran part of the 18 miles and joined in the 18-mile bike ride.

I am so proud of all four of my children. I often wonder if Charlie and Joshua would have had similar personalities to Jess and Samuel or different altogether; would

they have loved maths and football too, or singing and dancing? Each time Jess and Samuel reach a milestone like learning to drive, going to university, 18th birthday, it reinforces what we are missing, but sometimes in a nice way it allows me to wonder about our twins.

## Memory Box

We decided early on that we wanted to buy a memory box for all our twin's special belongings which I continue to add to, so much so it is very full now. I have particularly enjoyed collecting and buying mementoes with stars, angels, and Forget-me-nots which I associate with the boys. In fact, many of my friends and family also buy me star related gifts now too. I also enjoy looking for Forget-me-not flowers while I am out running. We have planted some in our garden and at the cemetery too.

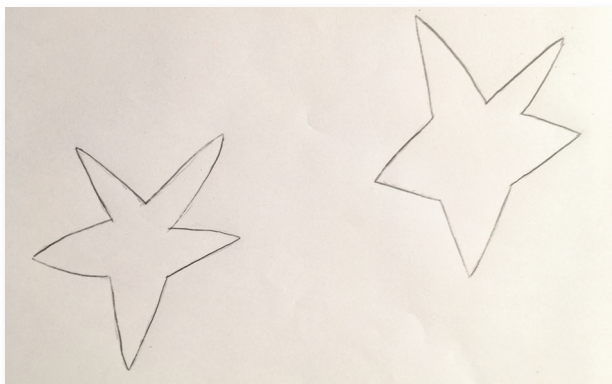
## Our Twins Resting Place

The twins are buried in a little village about 10 miles away from where we got married. Their grave is near to my grandparents and more recently my auntie. We take flowers and pots regularly. We love to keep their grave looking lovely.

## Remembering through my Work

It is important to me that my precious twin boys are always included and remembered. I love to say their names and to tell people about them. My work at Twins Trust is such an important part of my life too, as a direct result of my loss and as a dedication to Charlie and Joshua. They have changed my life and allowed me to meet some of my closest friends who have also lost babies.

I will continue to keep their memory alive and I am grateful to my family and friends who always remember them with me.



# Birthdays

## *Barbara Carson*

*About the author: Barbara has four children. She has two daughters, Rebecca and Lucy, and identical twin boys Ethan and Andrew. Sadly, Ethan passed away around the time of his birth. Barbara is a special needs teacher and following Ethan's passing, she hopes to work with children aged 7 to 18 years using her life coaching skills. Her passion is to campaign for change that will reduce loss in a multiple pregnancy.*

The twin's birthday now has a double-edged sword. Last September, Ethan and Andrew turned 5 years old. It is hard to believe that 5 years have passed since our world collapsed around us when Ethan died. When I was 36 weeks pregnant, his life was taken as velamentous cord was undiagnosed.

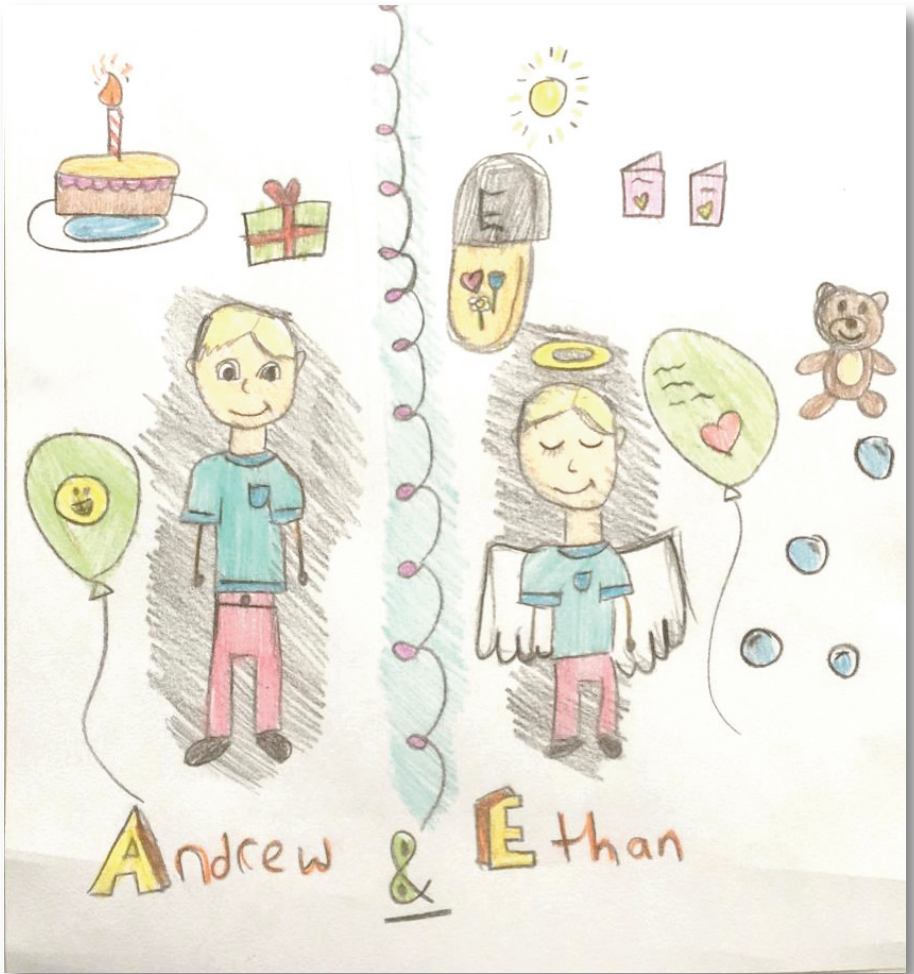
We often think how it would be to have both of them here with us, laughing, fighting and playing together. For us as their parents, the day of their birthday is a powerful reminder of our loss. Each year, we celebrate their birthday by having a small family gathering. Lucy and Rebecca, the boy's big sisters, love to bake two special cakes. One cake for Ethan has a little star on it and one cake is for Andrew with a football on the top. It is a day filled with great joy and great sadness. We have learnt how to cry and laugh in the same moment.

We visit Ethan's resting place the day before their birthday not on the actual day. We blow bubbles in the wind and leave Ethan a teddy and some flowers. We also have a small memory box for him in which we put cards and pictures.

We make their birthday really special for Andrew. It is huge celebration for us. We feel blessed and are so proud of him. We always hang up birthday banners for him around our home. We will continue with the same kind of celebration for future birthdays. We are doing what brings us peace and comfort and closeness to our boys.

Andrew knows that he is a twin. He carries Ethan's spirit with him each day. It is important to us that our family and friends have not forgotten about Ethan and say his name. Part of the process of rebuilding our lives has been to focus on the present as well as accepting the past.

I would give anything to plan a party for two but it is was not meant to be. Ethan's memory is safely tucked away in our hearts.



# Getting a Medical Diagnosis for one of my Twin Girls

*Mel Bentley*

*About the author: Mel Bentley is mother to twin girls, Florence and Beatrice, and a little boy, Alfred. Sadly, when the girls were 4 days old, Beatrice passed away. Mel loves to talk about Beatrice by honouring her and keeping her memory alive.*

## A much-wanted Pregnancy

It was a much-wanted pregnancy, our first, and we were thrilled to be blessed with two precious babies. But the pregnancy was difficult and there were complications along the way. Four days after the girls' premature birth, our beautiful Beatrice passed away. In those four days, we faced many obstacles with her health which were made more difficult by her tiny size. We had two hospital transfers between three hospitals, lots of medical procedures and so many upsetting and difficult conversations with consultants, neonatal staff and the surgeon who tried to give Beatrice a tracheostomy to save her life.

## The Medical Diagnosis - CHARGE Syndrome

We were told that Beatrice had a rare genetic disorder called CHARGE syndrome. CHARGE syndrome affects 1 in every 10,000 births, but in our case, Beatrice had a rare variation that affects 1 in 50,000. We were told that most doctors would never witness treating someone like Beatrice. Her trachea had not developed past her vocal cords. So, the fact that she lived for four days with no intact trachea was an amazement in itself. It was only possible by a small amount of oxygen passing through a cleft in her oesophagus.

## The Road Ahead

After Beatrice died, we were thrown into an indescribable routine of sitting by her surviving twin Florence's bedside. Florence still had a long journey ahead of her in the Neonatal Intensive Care Unit (NICU) and at the same time, we were trying to plan a funeral for our little Beatrice. We spent each day between NICU and the mortuary. Not a day passed where we did not visit Beatrice, no matter how hard it was. We had to be two different people - the parents who mourned for Beatrice and wiped their tears and the parents who had to be strong for her surviving twin who still had so many challenges to face. For weeks after Beatrice's death, I longed for, and even dared to hope for, a phone call to say that it had all been a mistake, but of course that did not happen.

After 5 weeks and 1 day in NICU, Florence was finally able to come home. Beatrice's funeral had been and gone, and we were thrown into our new normal, with no preparation and feeling like nobody understood our pain.

## Others' Reactions

We were sent cards congratulating us on the birth of Florence with no mention of her sister, and messages on how happy we must be to be home as a "family". It quickly became apparent that people did not know how to support us. We were left to deal with the loss of Beatrice alone. It felt as though people did not see or understand our loss. After all, in their heads, I had gone to hospital pregnant and returned with a baby. I remember someone saying to me "*at least you still have one baby*" and these words were just heart breaking. We had lost Beatrice, one of our children, our precious twin daughter and sister to Florence. We had lost the chance to experience being twin parents. We returned the twin pram and bought a single. We looked at the matching outfits we had bought for the girls knowing that only half would be worn. Florence has lost her twin sister, the relationship she should and would have had, and Beatrice has been denied everything.

## Returning to Work

Guy, my husband, returned to work, and I started my journey as a stay at home mum with Florence. I attended groups with her and without her twin sister. That was hard. I remember having to cancel Beatrice's place on the baby massage course. From the outside perhaps, it looked like I was coping but the grief continued to eat away at us.

We were terrified that something would take Florence from us. I would stand by her cot at night and need to hear a certain amount of breaths before I was able to leave. I also became terrified of seeing twins because they reminded me so much of what we had lost. I suffered my first panic attack when Florence was a few months old after seeing someone I had not seen during my pregnancy.

## Managing Grief over Time

In the years after Beatrice died, our grief has affected us daily. It is hard to celebrate Florence's achievements without thinking about what should be. Although it becomes easier to manage the grief over time, it is still always there and can be brought straight back to the surface by the smallest triggers. It has put a strain on our relationship as a couple, and affected relationships with friends and family, even severing ties entirely.

Since our twins, we have had two more pregnancies. These brought to the surface a whole host of new emotions, anxiety, and feelings of grief. A worry that people

would see this baby as a replacement or assume that we must be healed now. The first pregnancy ended in miscarriage, which felt so unjustified after all that we had already suffered. Thankfully, our last pregnancy blessed us with our wonderful son Alfred. The knowledge that he and his big sister will never meet is hard to come to terms with. We shall never have the opportunity to take a complete family photograph, and Beatrice's presence is deeply missed from all that we do.

As time goes on, we become more accustomed to managing our grief, but it will never go away. Beatrice is such an important person in our lives. It has always been natural to talk about her with Florence and Alfred as they have grown. Alfred is still too young to understand, but Florence knows what happened, and she maintains a very strong connection with her twin sister. She loves to make Beatrice drawings and gifts and will proudly talk about her to anyone who will listen. It is wonderful to see the connection that is clearly there, but so very bittersweet, as their relationship should be so different. Beatrice has left a hole in our family that cannot ever be filled, but she is still very present. I mother her in a different way.



# Talking to my Surviving Twin about his Twin Brother

*Allison King*

*About the author: Allison King is mother to 4 boys, Daithi aged 4 and identical twins Cathal and Liam aged 3, born at 27 weeks and Oisín who was born last year. Cathal was born fighting but sadly Liam was born sleeping due to complications caused by Twin-to-Twin Transfusion Syndrome (TTTS). Allison shares with us how important it is for her to make sure her boys know all about their brother who is a big part of their family.*

## Talking about Liam from the Start

Our sons know they have a brother in heaven. Daithi, our older son, was 20 months when the twins were born. Like all children, he is a sponge and took everything in. So, from the start we told him that Mommy had two babies - Cathal who was very sick in hospital, and Liam who was too small and had gone to heaven.

## On Birthdays

We have just celebrated our twin's third birthday. It marked 3 years since the boys were born at 27 weeks. It is always a bittersweet day. Our celebrations started with a visit to Liam's grave. The boys were delighted to bring the 'number three' balloon and a singing candle to Liam. Every time we sang 'Happy Birthday' to Cathal, he made sure everyone sang to Liam too.

## The Significance of Butterflies

We do not just remember Liam on his birthday. He is always on our mind and in our hearts. We speak about him daily. He is the butterfly that Cathal chases around the garden or he is a rainbow appearing to say hello. I do not remember when we started calling butterflies "Liam", but this has always stuck with Cathal. Since he could talk, he has always called butterflies "Liam" shouting out "There's Liam". We have a butterfly mobile over Cathal's cot, and we blow kisses to him every night. We talk to Liam and tell him if we have visited his grave, watered his flowers or tidied his tree in the garden. Cathal loves to talk about him.

All cards that we write, we draw a butterfly on the card to represent Liam. Our house is full of butterfly frames and photographs in Liam's memory. Family and friends also often pick up little butterfly ornaments, candles, and cards for us as it also reminds them of Liam.

## Questions about Liam

From time to time, Cathal will pipe up “Do you want to go visit Liam?” The boys love to visit and play with his toys or help daddy plant new flowers. My heart fills with so much love to hear them talk about him and yet it breaks my heart at the same time. He is still too young to understand fully but he is starting to ask questions now and we answer them as honestly as we can. Only recently, he asked me why he cannot go to heaven to see Liam. All I could say was some day we would all get to meet him again. It also saddens me when I see Cathal looking at his own reflection in the mirror or window as he should be seeing his double everywhere if Liam had survived.

Cathal has such a love for babies and is so sweet and gentle around them. My heart could explode when I see him talking to babies. I really believe this is because he is a twin and he is remembering the 27 weeks he had in utero with his brother. His love of babies helped us make the decision to try for another baby and he loves his new baby brother Oisín.

## Liam’s Garden

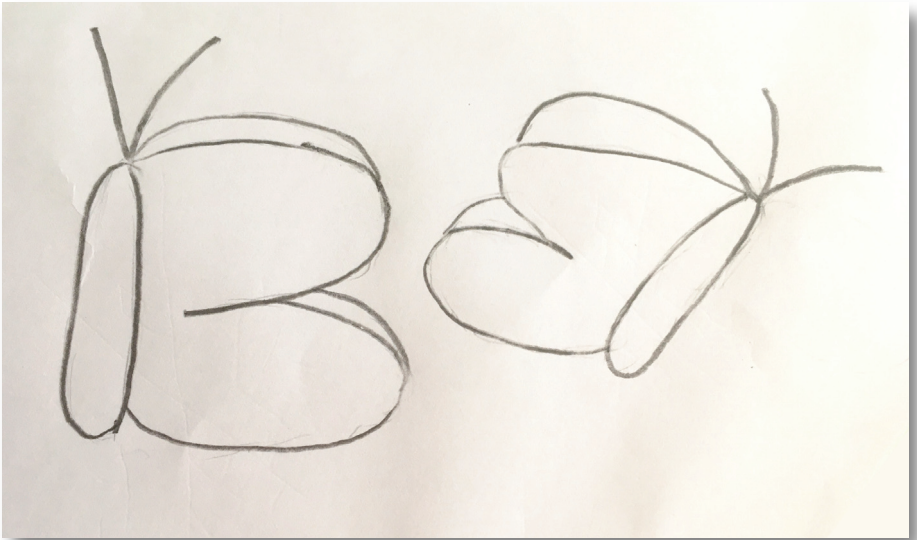
A section of our garden is called Liam’s garden. This is where we planted a tree on their first birthday and over the past two years have added more flowers, ornaments, and lights to it. We love to sit on the wall at Liam’s garden and have the chats.

Every Christmas, we remember Liam by hanging a stocking for all four boys and Santa gives Liam a new ornament for our tree. We were given a beautiful candle from *Féileacáin*, the Irish baby loss organisation, and we light this on his birthday, Christmas, and some days just because we are thinking of him.

It is so important to me that Liam is never forgotten, and he will be included in every upcoming celebration as Cathal grows. I will answer all Cathal’s questions as honestly as I can, and I will continue to share Liam’s memory with the boys.

Another beautiful way that we remember Liam is through his teddy bear. Cathal has a teddy in his room that was with Liam until we buried him - we swapped teddies so each twin will always have a little piece of each other.

I believe that there is no right or wrong way to remember Liam with Cathal. I just do what feels right for our family.



# Firsts

## *Ellie Curran*

*About the author: Ellie's much sought-after babies were due in early 2016. However, after a seamlessly easy pregnancy and without a lot of warning, Aidan arrived into the world too soon at 23 weeks. He was beautiful and perfect just not ready for this world. He lost his battle on 1st October 2015.*

*Donnacha waited until 2 October to meet his parents. He came into this world a little stronger than his brother. He fought a brave battle but unfortunately that battle became too much, and he was reunited with Aidan 3 days later on 5th October.*

*Aidan and Donnacha have without a doubt left their mark on this world. Following their deaths, Ellie fundraised to give something back to the Rotunda Hospital in Dublin and to help parents who would walk a similar journey. The **Aidan and Donnacha's Wings** initiative was launched @aidananddonnachaswings where bereaved parents are gifted a framed ceramic hand and footprint of their precious baby or babies. A priceless piece to cherish.*

## First Time to Hear about Twin Loss

Firsts are meant to be best because they are new beginnings. But as parents of Aidan and Donnacha, our twin boys that sadly did not survive in this world, there are so many firsts that are not new beginnings for us.

The first time it dawned on us that twin pregnancies were not always straightforward was two weeks before our twin boys were born prematurely. We attended an Irish Multiple Birth Association information evening where we learned of twins born that day and sadly one passed away with limited warning signs. Hearing this, we realised that although we were well past the magical 13 weeks stage and nothing concerning was highlighted at our anomaly scan, we still had a way to go for our twin boys to arrive safely. Little did we know what lay ahead of us exactly two weeks later when our twin boys arrived prematurely at 23 weeks.

## First Time to See our Double Buggy

We had to cancel the purple double buggy that we had ordered for Aidan and Donnacha. After the boys passed away, I clearly remember the first time seeing a lady pushing the same buggy we had ordered. I was floored and shocked by the impact it had on me. A couple of years later, with 19 months between our rainbow babies, we realised the same double buggy was once again on the cards for us. It took a lot of persuading for me to get one and it was only on condition that it was any colour other than purple.

## **First Cancelled Appointment**

I remember the day and time that I should have had my next antenatal appointment. Instead of being with my consultant planning the twins' birth, I put my head down on the kitchen table and cried and cried for what seemed like an eternity. I was feeling so empty as well as envious of the parents who had unknowingly taken my appointment time.

## **First Check-up following the Boys' Delivery**

On the day of my six-week post-natal appointment, my consultant's secretary phoned me to change my early afternoon appointment to a later one. I was grateful to be his last appointment of the day so I would not have to come out and see a pregnant woman next in line.

After chatting to my consultant for what seemed like a lifetime, I got the reassurance I needed that "yes, we would have a chance to have another baby". Even though leaving the hospital that day was gut wrenching, it felt like that chapter in our lives was possibly over and we could try to look forward to different new beginnings. I know now however that it will never be truly over for us. Aidan and Donnacha left such a mark on our lives and continue to be a huge part of so many people's lives.

## **First Trip Away after the Boys Passing**

I went to visit my sister in New York two months after the boys passed away. My husband, Shane was back in work, so he did not come with me. It had always been a dream of mine to visit New York at Christmas time. I was extremely nervous but felt the change of scenery would be good for me. While I was there, I was so consumed with finding two blue butterflies - that was our symbol for the boys. I could not relax until I found them. I wanted them for our family Christmas tree. As hard as the week was, to this day I am very glad I went. It did me good.

## **First Christmas**

Notwithstanding my trip to New York, the overall build-up to the first Christmas after the boys passed away was absolutely horrendous. Every morning I woke up wanting it to be over. Christmas day itself went as well as possible. Both our families rallied around us. We visited the boy's grave. There were lots of tears. We felt robbed of the happiness we should have had. I should have been heavily pregnant ready to give birth in early January. Instead I was on my knees in the pouring rain placing two wooden trains on Aidan and Donnacha's grave. But as we got into bed that night, we also felt a sense of achievement that we had survived

the day as well as a sense of relief that the day was over.

## **First Support Group Session**

Three weeks after having our twin boys, we went to a support group. We went not knowing what to expect but felt it was the next step to take in our grief journey. It was an eye-opener. It was the first time we realised how long this grief journey was going to last.

## **First Dream about the Boys**

I remember my first dream about Aidan and Donnacha so clearly. They were so small they could both fit into one car seat. In my dream, I was bringing them over to meet the girls on my basketball team in the gym. In reality though, how different my first trip over to that gym was after having the boys. No car seat, no babies, just lots of tears.

## **First Birthday**

For the boys first birthdays and anniversaries, we were in the very fortunate position to be cradling our one-week old rainbow baby girl Éabha. Needless to say, emotions were high. We celebrated with cake and released balloons and brought Éabha to meet her brothers at their grave. While the safe arrival of Éabha was so special, it is important to emphasise that she did not replace our twin boys. No baby can ever replace another baby. Every single baby is unique and precious. A baby born following the loss of a baby or babies is not a replacement; they are another precious gift for their family.

## **First Time I was asked How Many Children I Have?**

The first time I was asked had we children knocked me for six - it still does. I always said two which lead me to explain the journey of Aidan and Donnacha. Sometimes, I felt that I was supporting the person who asked the question by trying to explain to them that we don't mind being asked.

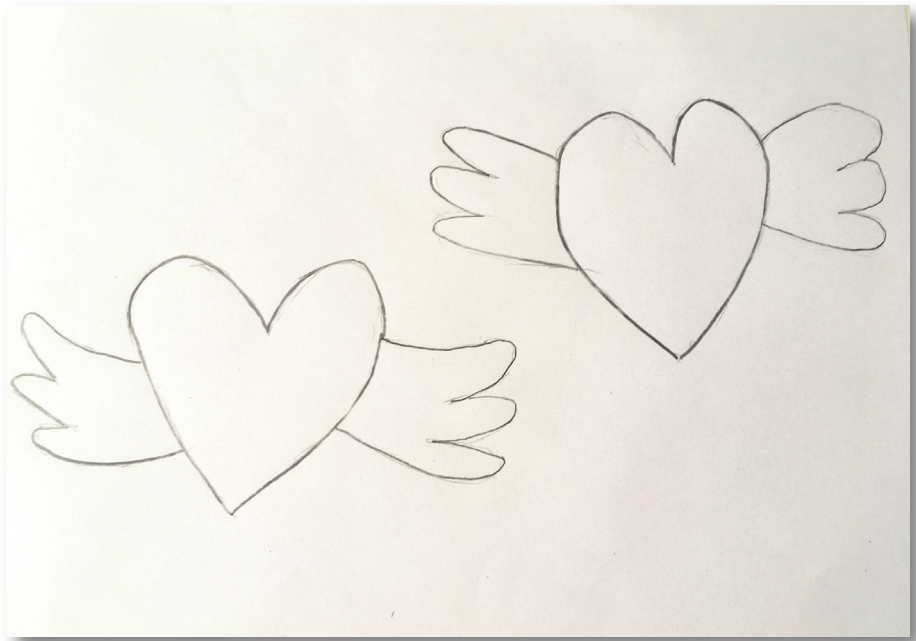
Since, Éabha was born the question has changed to *"Is she your first?"* or now *"Is it just the two?"* We have welcomed another sibling for Aidan and Donnacha, a baby boy we called Rían. So, my answer to how many children we have is always four - two in my arms and two in my heart.

## Firsts that have not become Firsts yet

The next big first should be the boys first day in Junior Infants. This is particularly emotional as we are both primary school teachers and my husband teaches in the school Aidan and Donnacha would have gone to.

Then there should have been Aidan and Donnacha's First Communion and Confirmations and all that goes along with these two special occasions. At all these events, we should be celebrating 'on the double'. Instead we must wait a few more years until it is the turn of their siblings.

The other firsts seem to be a series of events that have not happened and will not happen. We have a feeling of loss because of the memories that will not occur and milestones that will never be reached like their first tooth, first words, first steps, first holidays, first cut knees, first time riding a bike, first picture painted ... the list goes on and on. All of these firsts and many more missed.



# How my Surviving Twin Includes his Twin Brother

*Elizabeth Flynn*

*About the author: Elizabeth is a mom of three, identical twin boys Brian and Nathan and their younger sister Saoirse. The twins were born at almost 34 weeks. Brian was born sleeping and Nathan is now a healthy 7-year-old. She is a full-time working mom, juggling all things home, work and kid related while navigating the complex grief of losing a baby.*

## Remembering Brian from the Start

I was almost 34 weeks pregnant with identical twin boys when our world was turned upside down. We got on to this emotional rollercoaster of grief that no parent should have to endure. One of our beautiful baby boys had not made it into the world.

In the first year, every milestone that Nathan, our surviving twin, reached, it hurt. On their first birthday, I was so deep in my grief that I barely included Brian, our twin who had passed, in anything that we did. I think there was a fog over me. But then as the months went on, I started to talk to Nathan about his twin brother. I knew that he would not understand too much as he was very young, so we told him what we thought he might understand and used words that he was familiar with. Soon after, I was lucky enough to be pregnant again. It was important for us that our new baby girl was not seen as a replacement for Brian. I wanted to make sure that both Nathan and Brian were known as her big brothers.

We have never had to actually disclose to Nathan that he is a twin. He has always just known about his twin brother because we talk about him so often. It is the same for his sister Saoirse. She knows she has a big brother in heaven. Nathan is 7 now and Saoirse is 5. Brian is very much a part of our family and we talk about him every day. We have a tree in our garden that Nathan and his Daddy planted in Brian's memory and we call it Brian's Tree. Nathan and Saoirse spend time looking after it and watering it. Their Daddy also got a beautiful blue balloon made from metal and it proudly sits beside Brian's tree.

## Brian and Nathan's Teddies

When we brought Brian home there was a teddy with him and to this day, I do not know who gave it to him, but it is now Nathan's most treasured possession. We told him that Brian gave it to him, and he loves to tell people that story. We have a

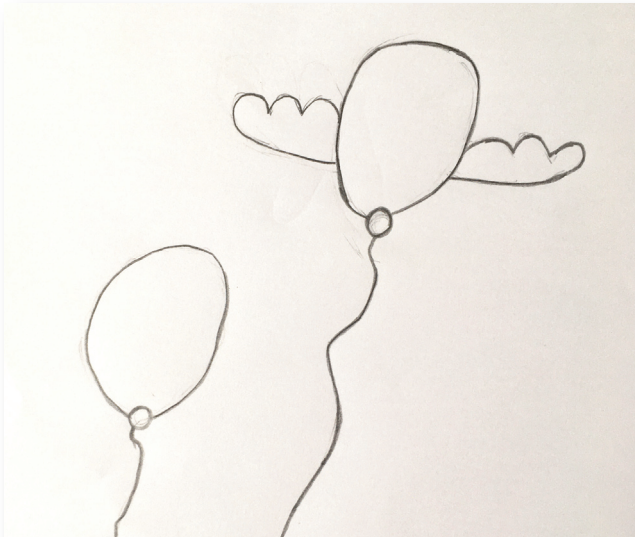
‘Molly Bear’, which I bought for my own comfort. It is a weighted bear and weighs 4lbs - Brian’s weight when he was born. Nathan took a shine to this bear too and we named him ‘*Brian Bear*’. Brian Bear sits on the end of Nathan’s bed. We have included Brian Bear in some of our family photographs and his Nana even knit Brian Bear a Christmas jumper for our annual Santa visit.

## The Boy’s Birthdays

On the boy’s birthday, we remember Brian by including either a blue butterfly or blue balloon on the twin’s birthday cake, even when it might not fit with the theme! There were two little butterflies on an Avengers Cake last year. On every birthday, we get two heart shaped balloons - one that we bring to Brian’s grave and one that we keep at home to remember him.

## Including Brian Every Day in Everyday Ways

Every night, when I help Nathan get to sleep, we say goodnight to Brian and tell him that we love him. There are some nights and days when Nathan asks the most heart-breaking questions and I answer them as best that I can. Sometimes, when we are going out or the kids are playing, Brian is included too. Nathan and Saoirse sometimes pretend to put Brian’s seatbelt on in the car and blame him on any messing that is going on. Other days, Brian does not feature as much and that is okay too. Neither Nathan or Saoirse will forget their brother Brian or hide his existence from others. He is their big brother, and they love him dearly.



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