



the
lullaby
trust

**“When my baby died...”
Parents tell their stories**

Parents tell their stories is a booklet published by The Lullaby Trust and written by a number of bereaved parents. The Lullaby Trust would firstly like to thank them for sharing their experiences with the reader, in memory of their child. The Lullaby Trust has chosen these particular stories to illustrate the different ages and circumstances when each death occurred. We are aware that these are difficult stories to read, but despite the content, trust that the reader will be left with a feeling of hope, as each parent has clearly illustrated.

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The photograph

Nicola died in February 1974 aged 2 months

Nicola was my second daughter who died suddenly and unexpectedly. Although she had been a 'near miss' cot death eight days before she died, we had no idea that she would die. She had been in the hospital for two days and no one could give an explanation for the 'near miss'. She had been seen the day before at a routine check with the doctor and health visitor and was a really healthy baby. I didn't even fear that she might die or have another near miss.

Fortunately we had taken a few photographs of her during her short life. One with each of the grandparents, one with me her mum and one with her dad, one in the crib, one in her bouncy chair and a couple with her sister Sarah. These were very precious when they came back from the developers and went into an album. And there they stayed. I hadn't thought of having one on the wall or around the house. Nicola had died but she was always with us. She was always talked about even when my son Andrew was born. She lived through the many things we did while supporting FSID (now The Lullaby Trust) although as life moved on we probably stopped talking about her.

One day, when Sarah was sixteen, we were shopping in the supermarket. Sarah had put a few things into the trolley which at the checkout I suggested she should pay for. She opened her purse and to my surprise showed me a photograph of Nicola in her bouncy chair which she had taken out of the album. She had suddenly felt the need to have the photograph of her sister with her. It really brought home to me that the photographs in the album were for all the family and that the value of having them there was something I couldn't begin to know. I was just so pleased that they were accessible and that Sarah had felt she could take one. I had given copies of the photographs to the grandparents at the time Nicola died but never realised how important they would be to the other children so many years later.

I have since had copies of one of the photographs made and keep one in a frame. Not that I need to be reminded but because perhaps others need to know without being told that there was another member of the family. I have also since learned that photographs are important but that the individual may wish to choose their own if possible rather than the one we choose for them.

Sarah is now to get married, a great excitement, and Nicola is again remembered and talked about because she would have been the chief bridesmaid. It's amazing how little details have been forgotten but not the feelings of the time. I myself am enjoying Nicola's photographs because I am searching all the family albums to make an album for Sarah of different times in her life. The photo I have chosen for her album is one of them together. It will be under the heading of 'Sarah with her baby sister Nicola, 12.12.73 – 5.2.74' on the same page as 'Sarah with her baby brother Andrew'. Andrew will be an usher at the wedding and Nicola will be there in the album.

Ann, Nicola's Mother



Heartbroken daddy

Annie died in April 1993, aged 21 months

Our beautiful daughter Annie had born seven weeks premature and weighed in at 4lbs 5ozs. I'll never forget watching a nurse pushing a trolley with what looked like a 'fish tank' on it, with a small blanket covering something even smaller. Then the Doctor called me over to meet my daughter. I was totally overwhelmed with feelings of joy, love, humility, helplessness, worry, concerns for both Annie and Julie. After a few weeks in SCBU, it was time for Charlie, Annie's brother, and I to bring our girls home.

Our home was 50 miles from the hospital at a place called Gutersloh in Germany where I was stationed with the Royal Air Force. Our life was getting back to normality, after the endless trips up the motorway to visit Julie and Annie. They were replaced by day trips to the local parks, feeding ducks, playing with her brother and her only holiday to Spain and they never argued at all in the back of the car. Just sat there holding hands and enjoying each others company. Together they were a joy to behold. Gutersloh closed and we were posted to Laarbruch, a lovely town, with more great places to explore as a family.

April 16th 1993

It was a sunny Friday afternoon, my car was packed, as I was off to the UK to watch the Coca Cola Cup Final. I kissed Julie and Charlie goodbye and wondered if Annie was awake for a kiss... Suddenly our whole world changed and would never be the same again.

Julie screamed out! I ran into Annie's room and found her slumped against the side of her cot, cold and lifeless...I picked her up and started to give her mouth to mouth trying desperately to see her cough, sputter and breathe. Sadly it was to no avail. Time stood still until the German medics arrived, who confirmed Annie had died, they then stood up, left her there lying in the lounge, The RAF medics then gently placed Annie in Julies lap, wrapped in a blanket. And we climbed in to an ambulance.

The next few days were a bit of a blur, the three of us flew back to UK for the funeral, I can't really remember much about the following weeks but one thing



that will always cut me to the bone whenever I recall it, was when poor little Charlie looked up said "I've got no-one to play with!" That broke our hearts.

We had a service of remembrance for Annie when we got back to Germany, which gave our friends and colleagues a chance to say their farewells and to show their support. As the service finished someone from the church choir started to sing Annie's Song by John Denver, but couldn't finish as he got upset, and the congregation finished the song. It felt like, and still does every time I hear this beautiful song, as if someone has their hands round my throat and is squeezing my adams apple. I have to say that the RAF at Laarbruch, especially all on 3(Fighter) Squadron, were totally fantastic in their support, and concern for us.

A couple of days later Julie was walking back from dropping Charlie off at nursery, when a couple of women she knew, looked up and crossed the road to avoid saying anything to her. Obviously this upset her greatly, we think that they didn't know what to say. I think I'd rather someone just say "How sorry they were at hearing your sad news, and I don't really know what to say." We were posted back to UK in July 93, and the people in charge of allocating housing to RAF personnel, said "Oh, you only have one child now, you don't need a 3 bedroom house!"..... People can be so tactless.

The first time we visited Annie's grave, a beautiful spot overlooking the Roman town of Caerleon in South Wales, on the radio we heard "Knocking on Heavens Door".

I went to FSID (now The Lullaby Trust) HQ a couple of years ago to train as a Befriender, and whilst sat having breakfast in a café, a big red double decker drove past with April 16th emblazoned down the side. Apparently it was the date for local elections. What a coincidence that was, with it being the date we lost Annie, and the reason I was in London. Life can be uncanny at times can't it?

Annie was born 7 weeks early which looking back was a blessing, as we were able to have more precious time with her. It still hurts ,and part of me wants it to hurt, but even though it does, I'm always left with a smile as I think of how lucky I was to have such a beautiful daughter even though it was for only 600 days. I know people say about the bond between Dads and their Daughters. I can understand that, but I can say that as Annie's, Charlie's, Billy's and Sam's Dad. I do love them all equally. Well maybe...

Neil, Annie's dad

Forever in our hearts

Lola died in September 2008 aged five and a half months

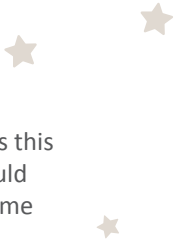
Lola Jane was born on the 8th April 2008. She was our 3rd child. Unlike her brothers Stanley and Frankie, she was born a week late. The week she was due we had heavy snow but the week she was born we had beautiful sunshine.

I remember the first time the boys bounced into the hospital to see her, "Wow a baby girl, we've got a sister". Within a few weeks she had gained a wardrobe bursting with beautiful pink clothes, ironically looking back most of which had a symbol of a butterflies on.

The next few months she settled in home well. Stanley (then 5) and Frankie (then 4) doted on her, they would bath with her, feed her, her bottle and even help with the nappies. Summer came and Lola loved being outside, whether in the garden overseeing the boys playing football or feeding the ducks in the park. More than most she loved nothing more than greeting the boys in the playground after school. Smiles and laughter all round. They were so proud of her.

The day before was Saturday 20th September, I had gone back to work for the first time leaving Lola with her dad, Jason and boys. They spent the morning at Soccer School and the afternoon was spent in the park and at a school friend's party. That evening was my mum's 60th birthday party, Lola met the rest of the family who had not yet met her. She was normally in bed by 8pm so I wasn't surprised when she fell asleep in my auntie's arms. She woke at 11.30pm and I gave her some bottle and put her in her car seat ready for home. We were all in bed by midnight.

After all sleeping well I woke at 8am on 21st September to silence which felt strange! I walked into her bedroom to see Lola was face down on her tummy, no movement. I just froze and screamed running away from her room, "NO, NO, NO, NO, I shouted. Jason ran into the room and picked her up carrying her into the front room. We rang 999 and started CPR, within 10 minutes two rapid response cars had arrived followed by an ambulance. The paramedics tried to resuscitate her without success then she was rushed into the ambulance and taken to hospital. After further attempts to resuscitate her, the paediatric nurse told us that she had passed away.



The next few hours we were in total shock, family were arriving at the hospital and the police had arrived and taken our house keys off us. Was this a bad dream? They explained to us they were to visit the house and would return our keys to us then we could return. This they did and gave us some leaflets on The Foundation for the Study of Infant Deaths (FSID - now The Lullaby Trust).

The hospital couldn't tell us how she had died and this we found so frustrating as our oldest son Stanley had a cardiac arrest at 6 months old. Luckily for us we were in the best place at the right time, which was the Royal Brompton and Harefield Hospital having been admitted earlier in the day with SVT. He had emergency open heart surgery and was put on Echmo, inevitably spending the next month on life support. He made a full recovery and remains healthy today. However, I was convinced Lola and Stanley's condition were linked. The Post Mortem results showed Lola had died from the bacterial infection, Group A Streptococcal Septicemia. Further tests from the Royal Brompton proved inconclusive.

Lola's funeral was on the 13th October and there was so many friends and family there, which was so comforting. Everyone wore an item of pink clothing and had a butterfly attached, there were so many flowers it was surreal. We chose the songs Somewhere over the Rainbow, which felt appropriate and Take That's, Rule the World which reminded us so much of her.

The next few weeks were so painful and I eventually picked up the leaflet from FSID. I needed someone to talk to outside of the family, to make sense of it all. I gave them a ring and their continued support and advice, I have received, has really helped me in some way to come to terms with our loss.

Jason has since done the London Marathon and I the Great South Run as well as numerous other events with our friends and families to raise funds for such a wonderful cause.

On the 14th December 2009, Lolas little brother Freddie was born. Lola will always be in with us. The five and a half months we spent with her left us with such great memories of such a beautiful happy girl who brought so much love and laughter into our lives, which will be cherished forever after.

Suzanne, Lola's mother

A Christmas story

Adrian died on Christmas Eve 1984 aged 7 months

Oh how I look forward to Christmas every year... the family get together, children opening Christmas presents, the smell of pine, Christmas Carols, going to church, the big turkey dinner, the whole experience, just the very thought of it, leaves me cold.

Celebrating the birth of one baby and the gift he gave to the world is difficult, no impossible, when all I can think about is the death of my baby who didn't even get to open his gifts under our tree.

Adrian was 7 months old when we found him dead, cold and blue in his cot on Christmas Eve morning. I was only 22 and his dad just 21. The three of us so young. The doctor, the police, the undertaker arrived and within one hour my beautiful baby boy was gone. He was buried on New Year's Eve 1984. Thus began my 'Christmas Story'.

"Away in a manger, no crib for a bed
The little Lord Jesus laid down his sweet head"

I still can't listen to away in a manger sung by children without crying. The smell of pine trees, we'd had a real tree for Adrian's first Christmas, always triggers memories. It was years before I let my subsequent children have Advent Calendars in the house. I found the countdown to that day unbearable. Adrian didn't get to open the last door on his calendar. I still have it and some of his presents, his dummy and clothes and lots of other silly bits and pieces in a box, Adrian's Box. It contains his whole, short, little life. One box.

But, it is only now, writing this piece, that I realise what a big mistake I have made. I have always allowed his death to be bigger than his whole life. Would I have done this if it had happened at a different time of year? Would the whole thing have been just a little less painful if he'd died on an ordinary day, in an ordinary month, one that I could fill with nothing but thoughts of him and of his life. My special day for remembering my baby.

Over the years, 27 of them to be precise, I have been so wrapped up in remembering his death, his death at Christmas, that I forget to remember his life.

For seven short months he brought me such joy. My first baby, my parents' first grandchild, he was adorable. Despite being a little bit premature he was thriving. He had just cut a tooth and the way he could zoom across our lounge in his baby-walker was to be admired. I loved settling down with him in the late afternoon and holding him while we both dozed before daddy came home from work. I was such a proud, new mum. I loved pushing him out in his pram, nobody could fail to notice what a handsome chap he was. And such a happy baby too. So content, so undemanding, so easy to look after. My Adrian, my baby.

I am not going to allow that black cloud to start creeping up as December approaches. His birthday, 26 May 1984, was a much, much nicer day.

In memory of the life of Adrian Hannibal – Born 26 May 1984.

Sue, Adrian's mother



My beautiful grandson had gone

Joshua died in February 2006 aged nearly five months

On 19 September 2005, my eldest child Tanya went into hospital to have her labour induced. It was her first baby. I was so excited. She had asked me to be her birth partner, along with her fiancé Lee. I was over the moon and felt extremely honoured. The thought of seeing my first grandchild being born was a bit scary. I wasn't sure how I was going to cope with seeing my little girl going through the pain of childbirth. I knew it was going to be difficult yet the most amazing experience of my life, one I wouldn't have missed for the world.

Joshua arrived in only three hours and was absolutely gorgeous. I loved him instantly. He was my grandson and I was so proud of him. I couldn't wait to show him off! I took photos, lots of photos, from every angle, every expression.

On 14 February 2006, my husband Paul, Tanya, Lee and I decided to go out for a Valentine's meal together. We were only out for an hour and a half because Tanya and Lee didn't like to go out and leave Joshua for long. He stayed at home with his great nanny and his uncles. When we got back Lee went home as he was working the following day. Tanya intended to leave Joshua with me the next day, as she was decorating their new flat so they both were going to stay the night.

At ten o'clock Tanya went up to get Joshua from his travel cot for his last feed. He was lovely at that time of night – all smiles. That is the moment that our world fell apart. I can still hear Tanya screaming now. "Mum, my baby is dead. Help me. My baby is dead!" Then it was sheer panic. I remember seeing her holding Joshua at the top of the stairs and I knew it was true. The terror on her face said it all. She was looking at me with pleading eyes like I should do something. After all, that's what mums do, isn't it? They make it all better. Except this time it wasn't going to happen. I didn't know what to do. I felt useless.

I started mouth-to-mouth, trying to follow the instructions I was being given over the phone. It wasn't working. He was just lifeless. It went on for what seemed like forever, until the ambulance men arrived. I can remember thinking that this is not real. It must be a nightmare. Everyone was so happy five minutes ago and, in an instant, everything just changed, forever. We

followed the paramedics to the hospital and Joshua was rushed off. After a short while Tanya was told that they should stop trying to revive Joshua. They needed her permission to stop.

We were taken in to see him – my grandson. He was just lying there, with all these machines all around him. My beautiful grandson had gone. Lee arrived at the hospital knowing nothing except he had to get there quickly. After all, no one could tell him over the phone that his son had died. How do you tell someone that?

The days and weeks that followed were a bit of a blur. I found it really hard to see my child in so much pain. Childbirth was nothing compared to the pain I had to watch her endure after Joshua died. I would have done anything to have taken the pain away, as any parent would. All she wanted to do was hold her baby. She didn't want anybody else.

Something I find hard to deal with is the feeling that I have lost my own son. I am grieving like he was mine. Well, he was, he was my grandson. Then I feel guilty because if I feel like this, then what on earth are my daughter and Lee feeling like? After all, he was their baby. I have to be strong for them but it seems like they are strong for me! Is that right?

Joshua's picture sits on my lounge wall, in pride of place, larger than life, and is a constant reminder of exactly how precious he was. I get comfort from his pictures and am glad that I took so many pictures of him. It's all we have now.

I hope one day that I will overcome my fear of this happening again, so that my grandchildren will be able to pack their bags and come to stay with nanny and granddaddy again. For now though, I feel as if I have been robbed.

Linda, Joshua's grandmother



I didn't have anyone to share my burden with

Martin died in August 1990 aged three months

When I lost Martin, I really did feel that the end of my world had come. I remember sitting in my GP's surgery and being given FSID (now The Lullaby Trust) leaflet depicting the couple on the front. I felt really insulted and very isolated, as if all single parents were being looked down on. At that moment I did not feel inclined to use the Foundation for support.

One of the things that I found when my baby was alive was how intense my love for him was. Without belittling couples, I feel it is harder to bear the death because your love for the baby is so condensed and solely for the baby. You are not sharing your baby with anybody and you feel extremely over-protective, so understandably the grief is even harder to bear.

I was lucky to have an understanding doctor who insisted on seeing me once a week. I became quite ill so he referred me to a psychologist. At the beginning of my therapy I really did feel that I was losing my mind. Now I believe that was because I had to bottle up my grief and I didn't have anybody to share my burden with. Whenever I saw the psychologist she encouraged me to talk, talk, talk and then I would end up crying. But it was the release that I needed.

It would have been really helpful if I could have had some advice from another single mum. When Martin died the 24 hour Helpline* hadn't even been set up. For single parents especially, the Helpline could be their only sanctuary when it's late at night or first thing in the morning.

It is important to get somebody to help you with the horrible parts before the funeral. I was fortunate that Martin's coroner cared enough to exceed his duties. When you're a single parent the prospect of paying for your child's funeral can seem horrendous. Fortunately my funeral director didn't charge me for Martin's coffin or the first car, so in the end I had a relatively small bill, and this was paid by the DSS. I would never have known that the DSS could make a contribution to funeral costs if you're on sickness benefit. Luckily my mother worked for Social Services and she told me.

The hardest part of coming to terms with Martin's death was the aftermath of the funeral. Coming back home, my two-bedroom flat seemed like a mansion without him.

At the beginning when I could not sleep, I would go into the spare room and push Martin's pram back and forth. I did that for what seemed like an eternity – I never knew why – but when I eventually sold his pram, it was the biggest wrench to sever the final tie.

I was very lucky to have good friends whom I could lean on for support. However, I found that I couldn't talk to my parents about how I was feeling. I knew they had the burden of their own grief. When I needed to offload, my grandmother was there to help.

My family and I have come a long way since that dreadful night three years ago. We talk together about how much joy Martin brought with him in the short time he was here. He was a contented little boy who brought a ray of sunshine into our lives.

Debbie, Martin's mother



He was too good to be true

Joseph died in February 2000 aged 14 months

We are all unique in experience but we all share the fact that our babies died suddenly with no preparation or explanation.

We may feel alone but there is comfort in the knowledge that we are not, and with the help of FSID (now The Lullaby Trust), and the experience and gift our babies gave us, we can hold up the torch and burn it brightly in what may seem a dimly lit society.

Joseph, a loving 14 month old, chubby, chuckly, blue-eyed blond with an abundance of curls, was full of life. I had felt he was just too good to be true and had expressed this many times. He truly is special.

Having experienced the pain and trauma of a third emergency Caesarean, which nearly resulted in the loss of our lives, every day seemed like a blessing and every moment of his life was filled with love and joy. But nothing could prepare me for the day that lay ahead. The shock of Joseph's death and the grief that would follow.

Joseph and I had spent a lovely day together alone. I had placed him in his cot and he looked peaceful. Later, I decided to make an attempt to wake him as he was very quiet. Although warm, he showed no signs of life and was limp when I picked him up.

I was alone in the house. I had no time to waste. My main concern was to bring my son back to life. The fear rushed through my body at such a force that I was trembling physically. I knew I had to stay in control. I tried to resuscitate him but there was no response and when the paramedics arrived and took control, I fell to my knees. My fear as a mother had become reality.

I was in a state of shock. This was way beyond my control – it was a nightmare. I thought I was going to wake up and Joseph would be running around the house laughing.

I became the focus of everyone's attention when all I wanted was to hold my baby in my arms and continue my life as his mother with his two brothers; it

was overwhelming.

Joseph died of SIDS and, unless you have experienced the death of a child, I do not think it is possible to explain how hard it is to understand what has happened.

The question – why? How do we begin to understand what has happened without reason. I found help with FSID. The level of empathy and the efforts that are made to create a greater awareness of understanding is of profound importance and reassuring.

Every day for me had been a struggle emotionally and physically. Body, mind and soul are wounded so deeply and the pain is so intense and isolating you wonder whether you will survive it. I had felt totally out of control and emotionally exhausted.

I had no reason to hold on to, no partner to share the loss, but I did have Joseph's two brothers, Peter and Rhys. Children give us a sense of purpose.

We do have a choice in life to give up hope or fight for survival. I asked for help and fought to survive. With the guidance of my counsellor, I can say I feel very proud to have been given an angel for 14 months. I want to share Joseph and celebrate his life and love and the experience he gave me to give hope to others who are in desperation.

Georgia, Joseph's mother



Chloe was like my little sister

Chloe died in December 2001, aged two years

My name is Mark Minchin, I am 17 years old. My two brothers, James, 15 years and Gary 30 and I are running the British 10K, in memory of our niece, Chloe Taylor, who was just 2 years old when she died of a 'cot death'.

I was only nine years old when Chloe died. It was the 16th December 2001. I remember my older sister, Sharon, had phoned earlier in the day to say when they were coming up for Christmas. Sharon, Chloe and Nick (Sharon's partner) had moved down to live in Wales. They had lived with us before so Chloe was like my little sister, she always came with us on holiday and I always remember her meeting me from school.

When Sharon phoned on that Sunday mum was dressing James and me up as shepherds for the nativity play. We had dressing gowns and tea towels on our heads! We had done the play and went back home. We had just got a computer so me and James went to play on it. I remember mum coming up and saying we had to go down to Sharon's straight away as Chloe had gone to hospital.

We all got in the car, including our dog and drove for what seemed hours and hours to the hospital in Swansea, none of us talked much and when we got there Sharon was crying. I remember going into the room in the hospital and seeing Chloe, she was laid on a bed wrapped up in a blanket. She just looked asleep. I remember James tickled her feet that were sticking out of the blanket to wake her up but of course she didn't. After what seemed like ages Gary, my older brother carried Chloe to another room that had a little bed and teddies sat on it. We had to leave Chloe there. I realise now this was the chapel of rest.

We all went back to Sharon's house and slept on her floor. It felt strange seeing all Chloe's things but she wasn't there. After a few days we came back home and then it was Christmas but none of us wanted to have Christmas that year. I had to go back to school and everyone was very kind. Chloe was buried back in our village churchyard six weeks later but I know we all felt it was forever.

We still have lots of photos of Chloe that are of course very precious. One is of her sitting on the slide in our garden with a very cheeky grin on her face which is how I remember her. James always remembers when he used to have lines of cars going across our floor and Chloe used to try and move them and put them out of line. He used to get very cross and she would laugh at him and run (or toddle!) away!

We will never forget Chloe.

Mark, Chloe's uncle



Our first grandson

Bailey died in February 2010 aged 24 weeks

Bailey Ian Jenkins born 15th August 2009 did not wake 1st February 2010
Reason: sudden infant death syndrome (commonly known as cot death).

As a grandfather you do not expect to lose your own children let alone a grandchild. When my daughter rang me at 1 o'clock in the morning to say that she had discovered Bailey (Bubba to us) not breathing we went straight to her.

It took us less than 2 minutes to get there, we tried to revive him, the police and paramedics took over. They took Bubba to the hospital with his mum and dad.

The not knowing feeling of why or how it happened - a child one minute full of life and just starting to get his own little personality, always laughing and smiling. He was my daughter's third child, her first son, our first grandson.

The last time I can remember hearing about cot deaths was when Anne Diamond lost her child - I did not think that this could happen to one of my grandchildren. When we received the word from the hospital that Bailey was gone it was like there was no reason to life. What was the point of a child just going to sleep and not to waken? It's not as if he was ill. It's not as if we had any chance to say our good byes before he left his mum and dad.

I know that if Bubba had been ill we might have been prepared for the loss but there was no reason. There were no signs. There was just the sudden feeling of emptiness. The no reason, the no answer to the only question - WHY?

The police were treating the house as a crime scene. We were not allowed to go into Bailey's room. We were not allowed to go upstairs without the police. It felt as if we had been found guilty of a crime and not as if we had just lost a child. But the child protection police, after they had done their job, told us they understood our grief and were only having to do their job. They took everything of Bailey's, bed, blankets etc, they took all the tablets etc belonging to my daughter and her husband. Their reason: just in case. What does that mean? It took days, no weeks for them to say no foul play.

They were nice about it I think... I had tried CPR on Bailey. I know I marked his chest and mouth. I told the police it was me who marked him not my daughter. I was worried thinking they might blame her for the marks but they told us they knew that this happens it was then they said they believed it was just a cot death.

COT DEATH - no reason. Just go to sleep and don't wake up. How do you get over this happening? Time is a great healer they say. I am 65 and know that it's not a healer but as time goes by it does become easier. You never forget. How do you comfort someone after such a thing? What do you do?

My family remember Bubba in every thing we do. We had a birthday party for him. My daughter and family named a star for him, they all say good night to him and good morning to him when they wake. We know he is not here but we all know he is in our hearts and that is important. My daughter is due a baby in December. We know it's a girl. The hospital and our doctors have been fantastic and have taken great care of my daughter. Some fools have said that she is replacing Bubba but this is stupid. You cannot replace a child. Any mother and father knows that each child is different no matter how old they are.

How do grandparents cope with the loss? What do we do? It's not our child! NO but it is our child's loss. It's hard to watch someone that has grown into an adult hurt so much you cannot take the pain away. You cannot say any magic words. You cannot rub it out and start all over again, you just have to be there for them that's all. Be there when they need a hug, when they are angry, when they need a friend. How have I coped as a grandparent?

We have three granddaughters - all little dreams, they help. But I found that by keeping Bailey's memory alive, by trying to make others aware and by fundraising, that this has made the hurt easier. Trying to get other parents to see that with care and attention this may not happen to them. I know that in some cases nothing can prevent it but maybe some day, some where they can find a reason and a cause and be able to prevent it. IF ONLY.

Brian, Bailey's grandfather



Running for Sidney

Sidney died in December 2009 aged 13 months

When my beautiful son Sidney was born, on 7 November 2008, it was if all our family's dreams had come true. Our only child, Betsy, was 10 but for six years my husband Ben and I had been trying for another baby through IVF. Miraculously, the second we decided to stop, I became pregnant.

Everyone was overjoyed, our new baby was like a little doll, enormous blue eyes, blonde hair, and his big sister was like a second mummy to him. I remember saying to Ben that he looked too perfect.

He was always an extremely smiley, contented boy who had so much love to give. At a year he was chatting away and starting to walk, but just after his first birthday, a week before Christmas, he got a cough and a cold, which kept him awake all night. We had the steamer going in his room and when he finally fell asleep we were really hoping that a good rest would help him to get better.

The next morning Ben brought me a cup of tea, and went in to check on Sidney. I heard a scream. It was clear that our boy had died but he just looked asleep and so peaceful. The emergency services arrived and after that I only remember the day in flashes. Much later on, we were told that he had experienced an overwhelming infection which was too much for his little body to take.

The most powerful memory I have of that horrifying day is how wonderfully sympathetic everyone was. Strangers were just phenomenal. They didn't know us but they were all visibly shaken. The Ambulance man, who was the first to arrive at our house, was fighting back tears and when we got to A&E a young punky-looking medic had to keep biting her lip, she was so upset. Later on we were supported by the hospital's lovely chaplain, and an amazing bereavement nurse called Sara. I just don't know how they do their jobs. We're so very grateful to them.

Two days after we returned home, Betsy answered the door to two uniformed police officers, at first I was shocked, until they produced an enormous bunch of lilies paid for by their team. One of the officers told us



how he had lost his young brother when he was only 12 and Sidney's death had moved him so much he felt he had to visit.

It's been so incredibly hard coming to terms with this tragedy. I remember ringing the Samaritans in desperation at 1am and I've been having counselling, but I spend at least 40 minutes of my session crying. Bereavement support has helped Betsy enormously. At the moment, Ben, Betsy and I are trying to choose words for Sidney's headstone. We're also about to go on our first holiday without him.



Channelling our energies into fundraising has given us and members of our family some comfort and our son was such a special person, he deserves to be remembered.

I'm running the British 10k for Sidney. The thought of running that distance makes me feel quite sick. However, knowing that I'm going to do this as a tribute to my son and to raise money for a great charity which is researching infant death and helping other people in my situation will keep me going. I might not finish until Monday but I will finish.

Amanda, Sidney's mother



What we had was so special

Milo George died in November 2008 aged eight weeks

The 6th November has always been an important date for my wife and I. We started our relationship as 16 year olds on the 6th November and then seven years later were married on the 6th November. This particular year our anniversary fell on a week night (always a nuisance) but luckily coincided with the grand opening of Christmas shopping hours in the shopping mall in Norwich. So we thought we'd take the kids (Isaac our oldest and Milo) to the mall for a pizza and to see the lights and Santa.

After eating and strolling round the mall, having checked Milo in the push chair several times throughout the evening (he was a very sleepy baby, so him sleeping the evening away was not unusual) my wife checked him again and found him to be unresponsive. Thankfully my brother and sister-in-law were with us to whip Isaac away and ensure he didn't see what was going on while I grabbed Milo and laid him on a bench in the mall and called for help.

To this day it still warms my heart to think of the number of people who stopped and volunteered to help that evening. Within seconds there were two community first responders with us and the ambulance was on the way. After 20 minutes in the mall and en route to the hospital, then another 20 minutes at the hospital, we lost our Milo man.

I remember thinking at the time that things would never be the same again. That we would always be stigmatised as the "people whose baby died". That people would always question our parenting ability. To some extent I was right. Things have never been the same, but that's not to say things are worse for us, we have bad memories, but we have 8 weeks of fantastic memories too, which is more than some families ever have. In his short life Milo George brought us so much happiness and joy – surely we can't allow ourselves to forget that and mope over him instead? Do people question our parenting or stay away from us because we've lost a child? No. Anyone that means anything to us knows that our lives revolve around our children, anyone else doesn't matter.

I don't think time heals because we forget, but I believe that we become better at dealing with what's happened as time goes on. That said there are

still times (fairly regularly if the truth is known), where my wife and I struggle emotionally and need to take some time out to compose ourselves. Secretly we both love these times. It sounds weird, I know, but I would hate myself if I didn't think about Milo every day and spend time talking about him with family and friends. He is still Isaac's little brother and our son – our memories of him can never be lost or taken from us. If they make us hurt a little bit or cry occasionally I think that's a small price to pay and he's more than worth it!

Having said all that, generally my wife and I (along with our families) have opted to take a positive approach to this tragedy. In the year after Milo died we arranged a dinner dance event on the first anniversary of Milo's death and my brother and I ran the London Marathon, all to raise money for FSID (now The Lullaby Trust). In 2009/10 we raised over £13,000 for the charity. This year we hosted another smaller event and raised over £1,300 on the night alone. Hopefully this will become an annual event in memory of our little man.

While I would love to spend more time fundraising for the charity, life is busy. We have a little girl Melia Belle, who is now 7 months old and threatening to crawl backwards more every day. Isaac is nearly 4 now and still fondly remembers his brother but has never been affected negatively by his loss. We have been careful with the words we've used in front of him, but have never avoided talking about Milo nor have we hidden our tears from him. Isaac is always involved with visiting Milo's grave and celebrating his birthday and while he doesn't really understand the gravity of the occasion he is interested in why his brother died and has made links between Milo and Melia. It's hard but it's just something we have to deal with.

Overall, we feel blessed to have been able to spend some time with Milo, we will miss him always, and cry frequently, but that's ok, the pain only reminds us that what we had was so special.

Gareth, Milo's father



Lucky to have had her, even for a short time

Karma died in December 2007 aged 11 weeks

On the 20th of September 2007 I gave birth to my first child at the age of 18, a beautiful girl called Karma. She was a healthy baby and my partner and I had planned to have her - we were really excited to be parents.

On the 7th of December I had arranged to go out, so Anthony and I left Karma with my sister, who was a great support to me as a young mum. We returned at 6am to collect Karma - she was only 11 weeks old so I was still too nervous to be away from her overnight. When we arrived home with Karma I gave her her morning feed. We loved watching her smile; she was so bright and happy in the morning. We laughed as she made funny noises.

At 8am we all went to bed, Karma slept in her own bed in the same room as us. Although we were in temporary housing at the time the house was in the best of conditions and was clean and maintained. Only 2 hours after falling asleep, I woke up suddenly feeling anxious. I had no idea why but I quickly turned my head to look over to Karma's bed and she was not in the position I left her in. I jumped up and screamed waking Anthony. I picked Karma up and she felt warm but I could feel she was still. I kissed her and put my finger on her to see if she was breathing, I hoped I was being dramatic but I was right, she wasn't breathing. My heart sank.

My partner was panicking and I knew I just had to stay focused. I had done first aid training so tried to resuscitate her. I was so scared I was going to make a mistake so I told my partner to call 999. The ambulance came in and began to try to resuscitate her. They asked me questions, which I knew we're necessary but felt intrusive. It was the most terrifying thing, not being able to do anything and not knowing if Karma was going to live.

The paramedics took her to hospital and after only a short time the doctor came to tell us that nothing was working and maybe it was time to give up. Determined this was not going to happen to us, to our daughter, I begged him to continue. Eventually Karma began breathing but we were told it was mainly due to the numerous adrenaline shots she had been given and

because she had been unconscious for so long there was a high risk of brain damage. I started to think of how my life was going to change if Karma did have brain damage but that I would be happy to have her no matter what.



The Children's Acute Transport Service (CATS) arrived by helicopter to assist and fly Karma to Great Ormond Street Hospital; if she became stable she would need intensive care immediately but unfortunately Karma was reliant on a machine. This was the point at which my partner and I had to make the decision to let her go. I remember thinking somewhere out there was another mother in the same pain as me, praying and hoping her child can be saved, but I knew mine couldn't and I felt selfish letting the CATS team stay there any longer when they could have the chance to help or save another family. We held her and said our goodbyes and she died.

In the numb days afterwards we were referred to The Lullaby Trust for help, although we had no idea at this point why Karma had died. After the autopsy it was heard that Karma was a healthy baby and the cause of death was sudden infant death syndrome (SIDS). I had lost my daughter and lost my identity as a mother and it was even worse knowing that her death could not be explained.

Within the year following Karma's death I slowly began to grieve and I dealt with her death by going to college and working in a nursery. One day I felt down and called The Lullaby Trust where I spoke to Marcia and it was so helpful just to speak to someone who had no idea of my life or situation and could just listen. At times I wouldn't even say much, I'd just think or cry. I only called twice as I felt that was all I needed - as I had my mum and sister - but at times I felt as though I didn't want to upset them and so being able to call The Lullaby Trust really helped.

A few years ago I decided I wanted to become more involved with those who had lost a child. I went to a Lullaby Trust Family Day and after meeting other parents I knew I had to get involved. I had just started University and now had a two-year-old boy so was very busy, but I wanted to make a contribution. It was suggested I become a Befriender and after training I found it to be a rewarding involvement. I am glad that I am able to support other families, especially young mothers, through such a difficult time. We will always love and miss our daughter Karma Nai, she was a lovely baby and we are lucky to have had her even for such a short time.



Zoe, Karma's mother



So proud to have had twins

Alexander died in February 2007 aged 17 months

We found out we were having twins at our first scan on the 13th of April 2005. We wandered around the hospital's maternity department in stunned silence. Then, after a while, we were like two school kids giggling and laughing, not quite believing it had happened to us.

They were born on the 24th of September 2005 at Barnsley District General Hospital by normal delivery. Harrison James arrived first at 7.47pm and Alexander Robert made a speedy arrival 8 minutes later.

They were such happy and contented babies, rarely crying and very sociable. There were always smiles for everyone. I was and still am so proud to have had twins, although trying to shop in any way, shape or form without allowing extra time to be stopped and cooed over was impossible. Although the youngest, Alexander took the lead with everything. He was so mischievous. He was the first to sit and crawl, and a week before his death the first to walk as well.

That fateful morning on the 9th of February 2007 was like any other. Ian had left for work and I roused my other boys to start getting ready for school. Ian had brought Harrison into our room during the night as he was unwell.

I made my way to their room to wake Alex, not something I normally had to do as most mornings they would both be giggling and jumping on their bums to make each other laugh. I called him which normally was enough to have him up and smiling but ... nothing. Standing at the door of their room I knew immediately something was wrong.

I can only describe what followed as an out-of-body experience. As I recall what happened it was like looking at myself carrying out mouth-to-mouth on Alexander and begging him to please come back. When the ambulance men brought Alexander down our stairs I remember just seeing his leg. I knew then really but didn't admit it to anyone. As the ambulance pulled away, Ian turned up, full of hope and fear. He drove us to the hospital and I was praying silently that I was wrong and that the ambulance men had performed a miracle.

Pulling up at the hospital, the ambulance was at the entrance with the attending paramedics. We both went and said thank you but their eyes and faces said it all to me. We spent time with Alexander at the hospital and then again when he was taken to Sheffield Children's Hospital to be looked after by the fabulous ladies in their bereavement suite. We spent as much time with

him as we could, saying our goodbyes and making sure he was 'comfortable'.

It was important to me that Harrison and Alexander were dressed the same for the funeral. They had always worn the same from being born and I didn't want this day to be any different. I couldn't bear to see Harrison dressed in the clothes and shoes that they both had previously so we went to get him new ones. I'll never forget their wardrobe crammed full of identical outfits. Harrison's clothes from the funeral day are now in a memory box along with toys and other things that were in Alexander's cot.

Nothing was ever kept from us by anyone. The initial checks made on Alexander showed an abnormality in his heart and we were given an immediate appointment for Harrison with the top paediatric heart doctor in Leeds. This turned out to be nothing serious and not a cause for death. As it turns out they could be mirror twins as Alexander's abnormality was a mirror image to a 'normal' heart which Harrison has.

I have to take my hat off to all the police officers involved in our case. The two officers from CID were fantastic. It was obviously very hard for them as well but they were so understanding and we never once felt under suspicion.

The verdict was sudden infant death syndrome (SIDS) and the paediatric pathologist Dr Marta Cohen commented on how healthy Alexander was and that his death could not be explained.

I feel it's such a blessing to have had twins as every milestone that Harrison reaches we know Alexander would have been there just before him but there is also a great sadness knowing that he isn't there to share it with us.

It's been over 8 years since Alexander died and in that time so much has changed for us, not least our decision to have another baby who arrived in October 2009. It was a hard decision but the right one for us I feel, although I am still, 5 years on, like a cat on a hot tin roof. I am over protective as a mother but I feel justified in this. I have suffered the worst loss any parent can ever imagine and this is who I am.

The heartache is still ever present but is more a dull ache nowadays, ever present but easier to live with. Alexander is still a very large part of our family, we fundraise in his memory and as a family we are creating a legacy on his behalf.

I would change what happened to us in a heartbeat but I can't so we carry on with our new 'normal' and I'm proud of what we have been able to achieve in Alexander's name.

Nicola, Alexander's mother

Georgina died in April 2002 aged 14 weeks



Georgina is my 2nd child a beautiful tiny but perfect baby girl with an amazing smile that lit up the whole room. Georgina had many struggles in her short life of 14 weeks and 2 days outside my womb and the 37 weeks that she was in my womb. Child of mine who gained tiny wings of gold and flew to heaven leaving behind many memories of our short time together. Georgina left behind a big brother Bradley, she now has a little sister Caitlin and a baby sister Scarlett who will never know her apart from the memories that we are able to share with her.


My youngest daughter was on the Care Of Next Infant scheme (CONI). She is now 19 months old and she was on CONI for a while longer as she had some health issues. Without CONI we would have to wait rather than being fast tracked through the hospital system. My middle daughter was also on CONI and she is now a healthy, happy 5 year old.

I also have a 10 year old son who was just 3 weeks shy of his 2nd birthday when Georgie died. Bradley remembers a lot of it when Georgie died. The apnoea monitor was invaluable for him he knew not to worry or panic unless it went off, as he was 5 when Caitlin was born he also did the resuscitation training with me. It all helped him feel involved with his baby sister and that nothing was going to go wrong with her. He was able to talk to the pediatrician and the health visitor about his worries and fears it reassured him and helped him know that not all baby sisters die like he thought, because the death of a child does not just affect the parents of the child it also affects siblings that that child may have.

On CONI I received:

- Weekly visits from my health visitor which were invaluable, enabling me to talk through any problems I had or worries about my daughter. I got lots of reassurance from her that my girls are not Georgie and that we are at a different place to where we were with her.
- Apnoea Monitor - we started with the monitor that attaches to the baby and when they were mobile i.e rolling around in the cot we then moved

to a cot monitor under the mattress. I took the monitor into hospital with me when they were born and they went on it right way. The midwives knew that my daughters were CONI babies so instead of having the normal paediatric check before they were sent home they had two checks, one from the normal paediatric doctors and one from a CONI co-ordinator paediatrician.

- A symptom diary where I could record anything at all from sickness to a snuffly nose. This helped me watch for changes in my daughter so I knew when she was becoming unwell before she did, if that makes sense? 
- First Aid training on resuscitation - this was done with my health visitor.
- With my first daughter I was also able to meet with a paediatrician before she was born to discuss any worries I had... which I found invaluable. I didn't do this with my second daughter but could have if I wanted to.
- Weighing Scales - My daughter Georgie had major weight issues. She would gain then lose, then lose, then lose. She was hospitalised twice in her short life of 14 weeks due to this, so weight is a huge issue for me. I weighed my daughters everyday and wrote it in their symptom diaries. Again weight is another indicator that they are becoming unwell.
- CONI passport, that is the front page of the red book - My youngest was really ill while we were on holiday and needed to see a doctor. As soon as I mentioned that she was a CONI baby they saw her right away rather than waiting the four hours they wanted me to. For me, the CONI passport meant that you see a consultant if the baby is ever taken to the hospital rather than a registrar i.e A&E or hospital appointments.

What CONI has done for me more than anything is given me the support I need to be able to enjoy my daughters rather than constantly worry that I am going to wake up and find them gone. Not that it takes the worry away completely, it's still there and always will be, but I am able to enjoy my children more than if they were not CONI babies.

Nicki, Georgina's mother



After thirty six years

Simon died in November 1974 aged two months

My son Simon died suddenly and unexpectedly in November 1974 at the age of two months. Thirty six years on I find that I often think about him and a physical sense of his absence remains. It seems to me that over the years my grief has taken this pattern. Immediately after Simon's death there was numbness; it was difficult to absorb the fact of his death. Then followed a period of disorganisation when I felt consumed with feelings and it seemed unlikely that I would ever again be able to engage with everyday life. Since then there has been a time of integrating Simon's death into my life and I see this phase as a continuing one. This continuing nature of my grief has led me to reflect on the often quoted view that "normal" feelings of grief last for about two years.

Actually I think parents are allowed to grieve profoundly for about nine months and then be tearful for up to two years. Beyond this time showing feelings may result in being told by others that you have not grieved properly. In contrast to this I believe that you grieve in proportion to the emotional space that the dead person has occupied in your life. A child or other special person occupies such a large part of your emotional space that a loss of this magnitude can be felt for as long as you are there to feel. I am emphasising the long-term nature of my grief because I feel that after two years a subtle process occurs in which permission for parents to be open about their grief is withdrawn and what I feel is perfectly normal behaviour can become pathologised. This perspective caused me to hide my feelings for many years and added to the burden.

At present there are three things that I find especially helpful. Firstly, I keep a sense of connection with Simon through one of his toys. In the early days after his death all his things were removed from the house. This was done by well-meaning people but I was not consulted. Fortunately the bathroom was omitted from this tidying up and I was able to secure Simon's small yellow duck. The duck now sits on my bath and it enables me to maintain a daily connection with him.

The second thing is contained in my reply to the unavoidable questions "How many children do you have?" For many years I have said "Two daughters and

I also have a son but he died when he was small". You will note I say have rather than had. I have given up worrying about how this may be received. If I am going to have a meaningful relationship with the person they need to know that this is important to me.

Thirdly, I talk to people about Simon when I need to. I find talking to other bereaved parents especially helpful. With them I can be myself and not worry about what I say. Their natural acceptance is deeply therapeutic and the best form of help that I have encountered over the years.

These are my ways of integrating Simon into my life and they enrich it. Others will find different ways. Overall I feel happy and content and secure in the belief that it is possible to live with such a loss.

Dee, Simon's mother



Lullaby Trust support

Befrienders

The Lullaby Trust has a country-wide network of trained befrienders, who are bereaved parents, siblings and grandparents. They give their time voluntarily to listen to and support others. Contact our Helpline if you'd like to be put in touch with a befriender; you could choose to speak on the phone, write letters or exchange emails.

Helpline

You can call our freephone Helpline on **0808 802 6868** or email support@lullabytrust.org.uk. The Helpline is answered by specially trained advisors from 10am to 5pm on Monday to Friday. On weekends and Bank Holidays calls are answered between 6pm and 10pm by trained befrienders. The information you give will be kept confidential. All calls are free, even from mobiles.

The Lullaby Trust website

www.lullabytrust.org.uk offers expert advice, research findings, Lullaby Trust publications to download and a dedicated section on bereavement support. There is information about our Care of Next Infant Scheme (CONI) for those who go on to have another baby. There is also a discussion forum where you can post comments and questions. The Lullaby Trust is also on facebook and twitter.

In Memory website

Our In Memory website offers parents the chance to create an individual memorial page for their child, and other family members and friends can also add their tributes. Please visit www.lullabytrustinmemory.org.uk

Thank you to those families who have written and given their stories to The Lullaby Trust for inclusion in this booklet.



the
lullaby
trust

For bereavement support:

Call: **0808 802 6868**

Email: **support@lullabytrust.org.uk**

Visit: **www.lullabytrust.org.uk**

The Lullaby Trust provides support to bereaved families, expert advice on safer sleep for babies; and raises awareness of sudden infant death.

The Lullaby Trust, 11 Belgrave Road, London. SW1V 1RB
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