

Personal Experiences of Bereaved Twins, Parents of Twins, and Their Carers.

We invited bereaved twins, parents of twins and carers to describe some of their personal experiences. We are grateful to all of them for their brave candour. We gave extra space to Kathy's story about the impacts of the loss of her own twin because it vividly illustrates the profound connections twinship can generate. Similarly we thought the cruelly long and complex saga of the life and death of Maxine's twins could help understanding of the distressing repercussions that often attend the low birth weight and prematurity that are so common amongst multiple births.

From Parents

Astride the Parent/ Professional Fence

Elizabeth A. Pector¹

The personal/professional fence makes a precarious seat but with a rewarding view. Since the stillbirth of my twin son five years ago, I've learned a lot about grieving, practicing medicine and keeping my balance.

Both when Bryan's death was discovered at a routine obstetric visit and when I was in hospital before delivery, the discomfort of my professional colleagues was obvious. As a way of coping with their distress, they limited conversations to a safe, technical discussion of facts, options and risks. This left me, a newly bereaved mother in shock, to translate the medicalese for my engineer husband, often ignored through these interactions although he was seated beside me. Although I had medical training, coping with my children's, as well as my own, complex needs was terrifying!

Flashbacks struck me at awkward moments. A year after delivery, the image of my stillborn son's bruised belly appeared before me when I saw a newborn patient's purple cord dye. Two years afterwards, I "saw" my son's casket when attending an elderly patient's funeral in the funeral home parlour where my son's service had been held. Such experiences reminded me to take my own pulse first, before rushing headlong to anyone else's crisis.

Fortunately, as a family physician, I do not confront dying neonates or

complicated pregnancies every day. Several perinatal nurses have tried to return to work after loss of one or more multiples. The bravest of them struggle for a long time to balance personal and professional lives and deliver effective patient care. Most find the effort exhausting; some, impossible. Nevertheless, mourning professionals of any sort who are strong enough to continue direct patient care and to share their own stories of loss with newly bereaved patients, are deeply appreciated by their clients.

I've expended hours in support groups and private counseling to maintain my own personal/professional balance and avoid falling into unhealthy extremes on either side of the fence: interacting without emotion, or turning a patient into my therapist by spilling my heart out to her. Chilling stories from ill-treated bereaved parents remind us that we must work responsibly through our own grief so we don't hurt patients with rude, unsympathetic responses at their time of greatest need.

Astride the fence I'm in a privileged position. As a participant in support networks, I hear feelings and opinions many parents would never dream of telling their doctors. My colleagues, on the other hand, want to help bereaved parents but don't know how. As part of my healing process, I sought resources for multiple birth loss, prematurity, special needs and other challenges. Through seminars, publications and a web site, I've shared parents' concerns and recommendations with caregivers who can help. Heartwarming testimo-

nials from grateful parents who were helped by my efforts renew my pleasure in being a physician. The magic of healing is that a burden shared becomes a burden halved. I know now that Bryan did not die in vain.

My own wounds are still healing. Envy, anger, or intense sorrow evoked by a newly bereaved parent's story can tip the barely balanced health worker off the fence. The bereaved professional therefore needs to take some time for introspection, counseling and participation as a "patient" in a support network before returning to educational or support work.

Just a Little Death

Julie Green²

It has been a long time since this death disturbed my whole being. I try not to think about it and put it to the back of my mind, telling myself "get on with your life now". But it is there, always there, somewhere. He was my son, our son, twin brother, grandson, nephew.

It was when I was much younger, able to "grow out of it". Nearly twenty years ago. Time would heal.

But you know it doesn't really heal, maybe just numbs the senses for times when the world is a smiling place. But when there are clouds and not so smiling faces it hits you with a thump. It comes up on you when you least expect it. Like Christmas, a time to be jolly. Like Jonathon's birthday (and

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Christopher's of course), a time for celebration. Then August! Sometimes, even when there is the most amazing sunset. So many days of grey.

But let's go back.

I was nearly 23 years old when my sons were born, 11 weeks premature. Jonathon rushed into the world, born "naturally", at 6.15pm on Wednesday March 10th, 1982, weighing 1000grams. Christopher followed, by caesarian section at 6.30, weighing 1260grams.

Both were born in a small rural community hospital. The doctor I had been seeing during my pregnancy stayed with me throughout the birth. The specialist I was seeing was over 2 hours away. A specialist obstetrician was called from another hospital. The anaesthetist was a locum doctor who just happened to be in the hospital at the time.

I was unable to see my sons until the Friday, as they had been transferred to the metropolitan hospital specializing in women's medicine and especially in pre-term births. My mother accompanied my husband and me to my first viewing. (Viewing seems a hard word but when your children are in humidicribs you view them. You can touch them and smell them but you really are distanced from them. No. Viewing is a good word.) None of us had been into a special nursery. I can't describe my reaction, my mother's was written all over her face. I am glad she was there with me. It is a special memory.

So began the many weeks of viewing and waiting and attending and learning and touching and holding and highs and lows.

It is extraordinary the life we led, like so many others in the hospital at the same time and the ones who still have to live this life today. So much for the arrival of newborns and the mental picture we have of the perfect family, all looking happy and everything in place and smelling like newborn babies.

Then came August 25 1982. This was the day that I knew I would be a different mother to lots of other mothers. My son died. We knew it was coming. We talked about it. We didn't want Christopher to suffer anymore but forgot about our own suffering. Having a son with disabilities may have been better than having a dead son.

From that day on I was different. I was always independent and strong.

From that day on I was stronger. No one in my family or Alan's had lost a child in this way, or lost a child. So we were the guinea pigs. Trying to support each other was tiring. Trying to support our families was more so. We put up such brave faces but underneath I know we both were suffering immensely.

How do young people tell old people that they understand the other's feelings and their reactions? How do young people cope with their mothers and sisters and brothers being unable to talk about the death or attend the funeral? How do young people move on in their lives?

There are times when you want to scream and shout and tell everyone that this is happening to you. Don't shut it out of our lives. Talk about him. He was real. Ignoring it doesn't make it or him go away.

As I said it was a long time ago and we never had the help of therapists or counsellors. So we did all that stuff ourselves. I don't think we have done too badly but I still don't think we have won.

Christopher is forever in my heart and never far from my thoughts.

A Double Tragedy

Maxine Ehlers³

Hindsight is a wonderful thing. I can look back over the worst period of my life and see how it might have been possible to cope with some of its overwhelming problems. The lives and deaths of our twin girls, Meghan and Adrienne, changed the direction of my life. I used every ounce of my strength and then had nothing left and felt I was losing control.

Shortly after the immense joy of confirming my pregnancy — my first — things start turning against us. One of our twins was grossly underweight. At 20 weeks we were told to expect the smaller twin to die either in utero or at birth. I never gave up hope, though I naturally focused my hopes on the larger twin. At 28 weeks I went into spontaneous labour. At birth Meghan weighed 1280 gms and Adrienne 450gms. Ironically Adrienne was the healthier: Meghan's severe congenital abnormalities had caused the premature labour.

The girls stayed together in intensive care at King Edward Memorial Hospital, Perth, Australia before Meghan was

transferred to a hospital in the next suburb to undergo the first stage of the surgery that was hoped to correct her blocked oesophagus and imperforate anus. Each day for six weeks I spent my mornings with Meghan and afternoons with Adrienne.

Meghan's chromosome abnormality was rare. It took six weeks to confirm what we dreaded. Of the 29 known cases worldwide of chromosome Q6 deletion all were severely retarded, most had died at birth, and the few that had lived suffered the same defects and growth retardation as Meghan. We were watching her fighting a losing battle. She lived for 3 months. The wonderful staff enabled us to take her home for short overnight stays. It was on one of these that she died peacefully at home in bed between us. This was the only show of love and normality we could offer her.

Meanwhile Adrienne battled on. With badly damaged lungs and weighing just over two kilos she came home from hospital after six months. Due to her birth size and prematurity her lungs were badly damaged. A nasal canula delivered a high concentration of oxygen. Once she was physically mobile the tubing was lengthened to allow her to move about the house.

I breastfed Adrienne until she was twelve months. I prided myself in keeping my supply alive, especially because she was so small and fragile. But Adrienne, like many, suffered from severe gastric reflux, lowering her enjoyment of feeding. I often had to sit with her for an hour at a time to ensure she had a decent feed. On many occasions she would project the entire feed across the room. All this made it very difficult for her to gain weight. On her first birthday she weighed barely four kilos, the size of some newborn babies.

Each fortnight I took her to the clinic to have her weight and oxygen levels monitored. I soon began to dread these visits. She had never gained the required amount and I always blamed myself. With the help of the Feeding Team we tried everything. Nothing really worked. What food we could get into her usually resulted in either a fluid or solid projectile vomit. It was very demoralizing.

I shut myself inside the house and rarely ventured outdoors.

At 12 months, Adrienne contracted a chest infection and had to spend two weeks in hospital. During her stay the gastroenterology team inserted a nasal gastric tube through which we could feed her from an electric pump in her bedroom. The infection had meanwhile further damaged her lungs so she required additional oxygen. Her pretty little face was covered with tubes. I could see past all the plastic, though I knew that most people couldn't.

Her weight soared with the overnight feeds. She became a happy chubby baby, her character blossomed. But unfortunately the condition of her lungs was not improving. During this time I became pregnant for the second time. We were very happy but the threat of having another child with birth defects weighed heavily on us.

Concern grew as to why Adrienne's lungs were not improving and it was decided soon after she turned 2 that she should undergo exploratory lung surgery. The outcome could go either way, we were to prepare ourselves for the real possibility of her requiring a lung/heart transplant.

On a crisp June morning we woke Adrienne early and took her to the hospital while it was still dark. She was in a beautiful mood, laughing, playing and flirting with a little boy in the next room. Then a nurse appeared smiling and kindly said "We'll take her from here". She picked her up and Adrienne's face changed from a happy smile to that of total betrayal. Her confused expression said "Mummy, Daddy don't leave me!"

Two hours later Adrienne's surgeon appeared and I knew straight away that the outcome was not good. He led us into the busy passage and explained that Adrienne's lungs were beyond repair and she would have to go on the waiting list for a heart/lung transplant. He was very sympathetic and spoke slowly, kindly and gave us hope for the future. But I was angry that he had delivered this appalling news in a busy hospital passage.

We sat with her almost every moment she stayed in ICU. We were given a room so we could be on 24hr call and wait for her to recover. She didn't. She was taken off life support

once to see how she would cope. She immediately began to fight against the tubing and wires. She thrashed, opened her eyes once, met my eyes and then Garry's and cried a pathetic "Daddy" before giving in again. She was placed again on life support and once again we waited. On the second night Adrienne's condition worsened

We reluctantly went to our room late only to be woken at midnight. Her condition was critical. We raced to join her and her entourage of medical carers. It was obvious that she was being kept alive by a nurse frantically pumping oxygen into her manually. Garry pleaded for Adrienne to come back to him. With tears pouring down my face I whispered over and over "enough, enough". She had fought long enough, far too long. The Director of medicine said it was time for the nurse to stop the ventilation. We both agreed. The many tubes were removed, she was wrapped in a white sheet and placed into my arms. We were then left alone, the curtains drawn around her bed. Garry and I sat with her between us and watched her colour change and felt her body cool.

We were left alone for as long as we needed. We were quietly asked if we would like to bath and dress her. We did this in the clothes we had hoped to take her home and laid her on the examining table. Garry then stormed off and walked around Perth for a couple of hours in the early morning darkness.

A few hours later Garry and I rejoined Adrienne. We sat together in silence for some time. The sun inched it's way into our first day without Adrienne. Soon the room was filled with our grieving families, they hugged and kissed me and gave me their condolences. I didn't move, I couldn't. I had nothing to say to them, I was barely coping.

Over the next few weeks I tried to keep my mind as occupied as possible. There was of course the funeral to organize. I was not as particular as I had been with Meghan's. A basic coffin and flowers: the rest just happened. Adrienne was buried in a track-suit and sand shoes and with her favourite teddy. After the funeral I waited and worried over the birth of our son. A

few weeks later, at 35 weeks, he had had enough growing inside a body that was so sad and stressed. He was born small and healthy.

I was so relieved that Charlie was healthy that I believed I could leave the past behind. But waiting for me were the same anxiety problems with breast-feeding that I had faced with Adrienne.

After seven tearful months I sought the help of a psychologist and spoke openly about the girls in the hope she would stop the anxiety attacks that dogged me every time I went to breast-feed my infant son. Driving home after the sixth session I was asking myself what I was getting out of it. What happened next lifted the weight of my grief.

Within a split second an icy cold sensation that started in my feet shot up through my body leaving me covered in goose flesh and Adrienne's voice filled my head: "Mummy, it's OK". She gave me strength, left me in tears and forgave me for all the times my anger of having to cope with her physical condition got the better of me. I never saw that particular psychologist again. I knew that I had to deal with it myself.

From Lone Twins:

My Twin, Myself and My Painting

Kathy Ramsay Carr⁴

My Twin. My brother James was born 20 minutes before me. We had our own language until we were 4. Then it became English, like...

"You isn't talking properly"

"I are."

When we were 3 years old, in 1955, we settled in Vancouver, to be near my father's identical twin brother and his family. Until we were 8, we shared everything. And then one day it changed.

James had been naughty and the teacher told him to stay back. We waited for him. My mother had been cross with us that morning. He never came home. There were search parties day after day.

The snow was melting down the mountains. There were ditches carrying the fast running water down to the sea. Nobody knew for certain what happened. James must have crouched down to look at the water,

slipped, banged his head and then drowned. His body was found on the beach two days later.

I remember that day sitting at the kitchen table waiting for him. I don't remember anything after that except waking up every night, willing him to appear like magic, lying in the dark behind a closed door, missing him, missing him. My mother would say goodnight, turn off the light and close the bedroom door. That was when the terrors began. I never thought of telling anybody. One didn't in those days.

I never saw my parents cry. Neither did I cry in front of them.

On the day of the funeral my parents sent me to school as usual. Later, the teacher told my mother that from the day he went missing, I stopped speaking and just stared out of the window, so she thought it best to leave me alone.

My parents thought it best too that we just "got on", so we didn't talk about him at all. All the photographs disappeared. I learnt in my 30's that for those first two weeks, my parents grieved James while I was at school, until my father said he couldn't speak of him anymore.

Unknown to me, my mother visited the cemetery every day for 5 months. The other day I asked her for some slides she had taken at that time, and there were many of ships leaving Vancouver. She took the photographs because she wanted to leave.

I went around humming and smiling. I was numb, I think, but I have no memory of the months that followed. Apparently my parents were relieved that I appeared so normal.

My mother got rid of all James' things, except for just a few, which she kept in a small cardboard box. She gave them to me a year ago, and it is like touching yesterday.

Myself. We left Canada 5 months after James' death and sailed back to England. At a small village primary school the other children thought I was strange. I had a Canadian accent, I was tall and gangly and hardly spoke. I was terrified, and thrown into an alien world of rough hostility. I remember feeling so ashamed of needing to go to the toilet that I did poo in my pants. Every day, away

from the teachers' eyes, there were terrible goings on in the playground; it was torment.

I was saved by my grandfather's generosity. He told my parents that having a dog of my own would help me get over James. He would pay for it but I should choose what I wanted: the terrier became my pride and joy.

My own "self" began to emerge. When I was 9, and becoming aware through the awful dull thud of my existence, that nothing would bring James back. I was cut off and rejected. I say this with no bitterness. I just accepted it. The world I felt loved in — the natural world, the skies, the trees, the birds and animals — was what I now draw upon to paint from. My memories become very vivid from this time onwards: walking alone every day with my dog, talking to the trees, sitting on their branches.

I learnt how to take myself away at night, by repeating over and over that I wasn't me, but although I was out of my body, I couldn't find James. I never accepted that he was dead.

I was searching for an answer.

First of all I felt angry with God. My mother was a Christian and I remember a book illustration of God as a man in white looking down from heaven, smiling. I hated him now. He took James away and had left me.

My mother gave birth to another son when I was 10, and he became the apple of her eye. My father didn't care for him much and retreated into his own world, angry most of the time. I retreated into mine, and began to draw and draw. I was in the woods and fields as often as I could.

As was common in the 60's, there was little communication between parents and children. Both my parents were very strict and had a very unhappy marriage. My father shouted until the walls shook and my mother cried. I kept my head down.

By the time I was 15, I knew I wanted to be an artist.

My life transformed at 18 when I was able to leave home and soon take my place in Bath Academy and began a new life.

I have always loved to be alone. I met like-minded people with whom I didn't talk about the past. It was the 70's and we were free to be who we

wished. I could be somebody different. All I had to do was create art for 4 years.

When I qualified in 1975, I already knew I had to do something different with my life. I loved Mexican art, the colours and bold shapes — and thought that I could travel to and fro between Mexico and Canada.

I left England in March 1976 and spent 4 months travelling throughout Canada, dreading the time I would reach Vancouver, but holding on to the hope that I would be given a new heart. I didn't know what I would feel, but I wasn't expecting the deluge of shock and hysteria that followed.

I visited James' grave, invisible with long grass and weeds, and walked through the basement of our old house, where the lines scratched by our father to record our growth, were still on one of the pillars, I sank into despair and total bewilderment. I wept as if to fill the ocean, and was suddenly desperate to fly to Mexico.

I arrived in Mexico City at night. At the airport the smell of the country hit me with force. The babble of voices, huge raw noise, everyone jostling, there was nothing familiar. I understood nothing and it suited me well.

I worked a 10 hour day with Mexican people. I was the only designer. The way of life was precisely what I wanted. I could be anybody; it was a new beginning. I struggled so hard just to understand the new life on a survival level that when I cried myself to sleep at night as I often did, I never questioned why. I had no intention of returning to England and was aware somewhere in the back passages of my mind that I was on the same continent as James. But I dared think no more than that.

I lived in Mexico City 8 years in all. I think this immersion in another culture and personality gave me the opportunity to bury my brother. I wanted no attachment to my family, and no reminder of growing up without him in that lonely place that was my head.

For the first time in my life I could separate my present from my past, and it was no coincidence that the country where I felt comfortable was one that held no taboos with death.

Twins Again. I married at 30 and became pregnant with identical twin girls. The day I was told there were two babies, it was as if I had known it always. I remember raising my head to the skies and saying thank you. It was my reward.

When I eventually returned to England to settle — in the village where my parents were living — the twins brought my parents and me closer together, but we still didn't talk about James.

3-year-olds ask questions with a bold directness that demands satisfying answers. Kim and Azul were intrigued that I too was a twin, but wanted to know where James was now.

This was the catalyst for change. As I told them the facts, I realised with amazement that I could break down in front of them without feeling shame. Their arms came up around me from each side, and I was held and comforted. Their comprehension of twin loss was total, I was the child in those moments and I felt wonder at the strength of their love for me.

My third daughter, Ione, was born that year. Her relationship with her older twin sisters has taught me a great deal about being one and being one of two.

As Kim and Azul did everything as one, and usually spoke to Ione simultaneously, Ione relied on her wits to stand her ground. She decided that she and our dog Charlie were also twins and therefore equal. I could understand her feeling at 4 that if you weren't a twin in our family you had no power. Kim and Azul were twins for the fourth generation running.

My Painting. I began to paint when my youngest daughter started nursery school and as I look back over these last 10 years I draw a parallel with the gradual repair of my soul. I don't know how else to put it.

As painting became like a sustenance so too did the need to think about what happened to James and me. Until this point any thought of him produced total terror.

One day I looked at some black and white photographs of ourselves on a beach and I decided to paint a series of paintings of the two of us.

As I worked on these, the same thing happened again and again. As I drew his face, so sure that it would emerge from my memory, it didn't. In exasperation I would take a rag and with rage would smear the paint. I would stand back and see a ghostly impression. This is what the painting became. My figure stood there next to him, but he was partly erased.

I gave myself over to what then happened, and as I painted, he began to float, as if he was ephemeral. I completed four of these, and in every one he was partly obliterated, sometimes with shapes emerging from behind him as if he had wings, partly covered with white cloud. Most of his body was complete, but it was always clear that he was not really there at all.

Having finished the pictures, I put them away in a drawer, where they still remain. They were hard to do, and it was an extremely painful procedure, but I know now that they were the beginning of a healing process.

The paintings' titles too are significant, "Night Solo", "Life is an Ocean", "The Daydream", "The Journey". The paintings are narratives, a visual poem, or a piece of music. One of a beach I called "Prelude to Sea".

Three years ago, I heard of an organisation called the Lone Twin Network.

The first time I attended, I was bowled over by the numbers there. Except that if their twins were present, there would have been 200 and not 100. This was very empowering.

The Network has given me, as to many others, a release from isolation and friendships with those who have shared the same experience.

At home, with my own children, I lay an extra place on my birthday for James. I light a candle and place it in front of a photograph of us together. This feels right. I am paying homage to my brother, who I think of now as my guardian angel. This awareness came to me as I painted. It is when I feel very close to him. I would rather he was alive, but I transcend his death through paint, colours and form.

It has taken me a long time to reach this stage, 40 years in all, but the creative process has enabled me to accept what is irreparable, lost forever. As a consequence, I have much to be

grateful for. I have new conversations with my parents, a deeper sense of understanding, and forgiveness too, for they suffered unimaginably. Furthermore, through bringing art into my daily life, I have been able to paint through all my anger and confusion and come to terms with my life as an individual. I can spread myself and release what I have to give, for as long as I am to live in this world.

See page 247 for colour reproductions of Kathy's paintings.

Sharing A Bond

Susanne Brink Larsen⁵

I was born in 1952 about 3 months early, and I lost my twin brother the day after our birth. I have always known about this but it was never discussed much at home.

I have felt guilty about his death because my mother told me that I had been lying too close to him, causing a lack of lung development. Today I know this is not so, and that boys do not survive premature births as well as girls.

I have always felt something was missing, without being able to say what it was. It would have been nice if there had been two of us and I have felt very lonely. I have had difficulties connecting to people, perhaps because I always was afraid of losing someone.

I came in contact with the Lone Twin Network by reading an article by Abeline Glahn and it started a lot of real emotions I had not felt before.

I attended Joan Woodward's lecture in Copenhagen about losing one's twin. The same emotions arose in me. That evening there was to be a meeting for lone twins at which we were put in groups according to when we had lost our twin. It was good to see that I was not alone and we shared many similar experiences.

At the end of the meeting we all agreed to form a Danish Lone Twin Network and that we must meet again. It was a strange feeling to go home afterwards. I felt so excited. Some of us have used the Network more than others. We who lost our twins during or after birth use it the least, as we share fewer experiences. But the possibility is always there if you need it.

In the group there is mutual understanding, togetherness with people with whom you share a bond.



Susanne looking at the church registry where she found the name of her twin brother, Lars. "It was a good feeling to see his name in writing. This was my documentation that he had actually lived".

It has always been difficult for me to show emotions and to hug people, even my closest family, but last time, when we left for home, the most natural thing in the world was to give a goodbye hug. Only in my car on my way home did I realize what had happened: I had been close to people in a completely different way.

A Special Connection

Olivia Monaghan⁶

As the twin of Lea Michelle, I have found that my feelings and my thoughts about her have changed over time and no doubt they will continue to change as I grow older. When I was younger I felt that I shouldn't pry about Lea Michelle because I didn't want to upset Mum. But she has always talked to me about her since I was two. As I have grown older I have no trouble in questioning my parents about her. One lingering emotion that I discovered not long ago was guilt. Not the eating-away at conscience kind, more of a curious guilt.

Lea Michelle died one hour after birth because her spine was not formed properly. As a young child I found this hard to grasp, but now I understand it completely. I remember asking my mum, "Mum, did Lea Michelle die because I took all the food?" These

days my mother and I laugh at that kind of question, but in looking deeper, I realise that I always felt that it was my fault. How, I did not know, but who else's fault could it have been? There were just the two of us in that womb, so I thought it must have been my fault.

I often ponder what it would be like if Lea Michelle had survived. What would we have had? My older sister and I have an amazing connection, as I do with my two older brothers also, but I wonder what that special connection of twins would be like.

I do not see why I should feel at loss because I talk to Lea Michelle all the time, whenever I can't sleep, or when I have a problem too big for my shoulders alone. I always talk to her, and always feel one hundred percent better after I do. She is my Guardian Angel, and sometimes when I have told others about this they give me a bit of an unbelieving look.

When people give me these looks I just tell them about the back surgery I underwent when I was thirteen. Coincidentally, I had an extra vertebra and rib on the left hand side. How ironic that I had to undergo surgery to remove those bones, when my twin sister died because her spine wasn't fully formed. Now I knew that I had extra bones which may have saved her life. On that note, however, I am not fighting an inner battle as to whether to hold myself guilty of Lea Michelle's death: there was nothing anyone could do about it.

Now I don't feel responsible or guilty in the least, because my doctor told me that my recovery after surgery was above the average for my age group. I don't think that was just me, I had someone very special and very close to my heart looking out for me.

(Olivia was born in June 1987)

The One I was Looking for

J r mie Damoiseau⁷

It is often said that twins share particularly strong links. And that the loss of a twin may nearly overwhelm the living one. But what about the twin we never knew? What are the consequences on the life and the story of the one left behind?

I am 23 years old and a French film student. I always felt that I was, or would be, part of a sad or even

tragic story. But I didn't know which, or even whether it was some kind of fantasy. I have a 3 years older brother, and I more or less let him move away from my world. To my bigger regret I felt my relatives and friends didn't and couldn't understand the world I was living in. I had a lot of dreams and ambitions. But I later came to realize that some part of me was missing if I was really to fulfil my ambitions. I often couldn't finish what I started or compromised it half way through.

A few months ago, I went to see a psychotherapist who uses a technique originally discovered to help the autistic express themselves. With the help of the psychotherapist, the patient taps randomly on a keyboard and unconsciously produces an understandable and meaningful text. So I went and did it. And my text revealed extremely profound things I had no idea of. At the very beginning it said:

I fear losing from the birth,
I lost my brother at birth,
It roots difficulties in me,
I cry in fear of losing everything since.

I was stunned at first: it was so weird to imagine I could have a twin or had lost a twin. And my parents had never told me such a thing. But at the same time the idea of a twin really appealed to me, even pleased me. It would explain so many things... When the session stopped, I felt unbelievably lighter as if I had expelled a weight from my stomach.

So I went to talk to my mother because there was something missing. She said that the gynaecologist had told her that she was expecting twins but she had been surprised and hadn't felt that way. Later, on the ultrasound, there was only one baby! She thought the doctor had been wrong and didn't think about it anymore. She hadn't lost blood or anything.

It may sound strange but it all made sense to me. The idea that I had lost a twin before I was even born linked all the pieces of the puzzle. Some episodes in my life took on new meaning and coherence. As an example, I have never had a girlfriend, even though I would like one. But I realized that I had in fact always been looking for a kind of sister, instead of a girlfriend. That has probably confused my approach to love and sexuality. It also explained the way I looked

at myself, why I liked to look at myself in the mirror. I could now give words to things I couldn't express before, I now really knew who I was and why.

From Those Who Support Them

Pioneering Memorial Service for Fertility Losses

Meredith Wheeler⁸

A child dies — but nobody arranges a funeral or memorial service, no one sends flowers to the parents or offers condolences. Sounds preposterous, yet this happens frequently in the field of fertility, where patients can easily accumulate “invisible losses”.

Consider, for example, the situation of a couple who decide to terminate one embryo that is part of a large multiple pregnancy — a multifetal pregnancy reduction. Such painful decisions will often be kept secret from others. In any case there is no ritual to channel the feelings of grief, guilt and pain connected to this choice.

Likewise, couples who undergo assisted conception techniques such as IVF are likely to be left with feelings of sadness, confusion, guilt and anger when treatment fails (which it does, about 85% of the time). They may even have seen their living embryos under the microscope before transfer to the womb — only to discover weeks later that implantation hasn't worked. Since fertility problems and treatment are often kept private, family and friends may have no idea of the stress that the couple is experiencing or their need for understanding and support.

No other generation has experienced situations quite like these — the backwash of 21st century hi-tech medicine. Up until now, no ceremonies existed to acknowledge, honour and grieve these hidden losses. The lack of external validation encourages a conspiracy of denial. Feelings bottled up often resurface later in life as depression or illness.

Recognising that there was an unmet need in this area, two other women and I (all counsellors and all with some personal experience of fertility losses) put together a special service. We pooled our resources and reshaped a service devised by a patient support group in Canada to suit our own goals: a non-denominational healing ritual for fertility losses

with many opportunities for active participation by those attending.

For example, everyone in our ceremony is invited to light a candle for the child who was not in life — including children never physically conceived. There is a generous bouquet of colourful flowers in the centre of the room with scissors and secateurs. Everyone is invited to cut off a blossom, representing their “lost” child and float the flower head in the central bowl of water. Time is provided for messages to be written to any “missing” children — and these are ritually burnt outside shortly after the main service ends. Most people participate using every means offered.

The service lasts about an hour and includes taped music (everything from Bach to Van Morrison) and readings — increasingly, over the years, original poetry and prose by those attending. Normally around 50 people attend — roughly a third are couples, the rest are women who come on their own or with a friend.

The feedback has been encouraging:

It was good to see my partner grieve openly — and to share our sadness with others who understand.

Tears came and for once they were cleansing. The whole ceremony was very beautiful. Everything was simple and accessible and I really valued being able to participate. It made me feel part of something rather than being separated and isolated and alone.

Many thanks for providing such a nurturing and healing day. I felt the atmosphere was containing, grounding and relaxing...enabling me to get in touch with grief without being overwhelmed by personal or collective material.

This moved me further along the path towards reconciliation, healing and growth. I will certainly attend again next year and would love to take part...

Inspired by the response, we have run the service in London every spring since 1999. Some people return year after year. One person wrote on a feedback form that she was particularly conscious of:

How I've moved on since I came to the service last year. The intensity of my grief and pain has lessened. Yet I am also able to get in touch with my feelings of loss, which are still there and needed an outlet.

Although it may sound like a sad occasion — and there are tears — most people find it cathartic. The mood at the end is usually one of lightness and release.

The service is now sponsored by the British Infertility Counselling Association (BICA) and More To Life, a patient support group linked to ISSUE, a nationwide support association for fertility patients. In 2002, the ceremony also was run in Scotland for the first time. We hope to seed the idea in other communities and copies of the service are available to anyone planning similar events.

A weekend workshop entitled “Letting Go — Coming to Terms with Fertility Losses” now runs in association with the services for people wishing to do deeper work on the theme of ‘coming to terms’. One major exercise in that workshop involves each person drawing a chart or graph of their fertility history or journey — the key events, the setbacks, the dead ends. These are shared in small groups and can be surprisingly illuminating:

It really made me focus on what had happened and why. It also made me realise how much I'd buried. Talking through my experience with someone who really understood was immeasurably valuable. Although ‘normal’ people can be sympathetic, they can never know how devastating infertility is and, for the first time, I felt able to express my grief, which has been kept hidden for so long.

Cobblestones are used to make concrete the unwelcome burdens accumulated along the journey — such as sadness, anger, jealousy, resentment and self-blame. These stones are labelled and “decorated”, then positioned on the big fertility-path drawings. We also did a powerful exercise holding the stones, feeling their weight and finally releasing them.

The group attend the service on Sunday afternoon together, most bringing their stones to leave at the altar in a conscious gesture of letting go.

Further information about future services and workshops or a copy of the London ceremony are available from the author.

Telephone Support for Bereaved Families

Barbara Read⁹

When the Multiple Births Foundation Telephone Advisory Service was established in 1994, operating from London, we had not realised how important its role would prove in supporting bereaved families.

I was the main operator and dedicated about three hours, four times a week for pre-booked telephone calls. All calls were documented which provided a record of previous conversations and helped with analysis of the service.

There are obvious differences in working on the telephone rather than face-to-face. The callers have anonymity and, of course, the option of ending the call at any time. The professional meanwhile is deprived of non-verbal communication such as the client's body language. Voice and ear become vital; the voice conveying ones feeling about what the ear is hearing. If the counsellor sounds rushed, distracted or tired this will inevitably suggest that we, along with others, cannot bear to hear their story. Meanwhile the client's voice often provides clues as to whether they are feeling tentative, fearful, flat, sad or possibly depressed.

One caller had great difficulty in speaking, her sentences were clipped and she asked unusual questions about dead babies and their bodies. She had also said that she might have to "hang up" without warning. I knew that there was something different about this caller and what she wanted. I felt she was frightened of something, so I reassured her that she could tell me as little or as much as she felt happy to do. It transpired that she had suffered an early miscarriage of twins — at 11 weeks — and had buried their remains in her garden. She had told no one and was consumed by guilt and fearful that she had done something illegal. I was able to reassure her that she had not committed any crime and said she could call me again if she felt this would be helpful. I also gently encouraged her to seek professional help locally. For this client the

anonymity of the telephone had probably been crucial.

One has to avoid making assumptions about the client's needs. A client who contacted me early in 2001 said life was very difficult because one of her twins had died in utero at 20 weeks and the other little one, delivered early, was still, three months later, in intensive care. She also had a healthy pre-school toddler at home and was struggling with how she "should" be managing her time.

The focus of our work together was very much about the decision she was making about how she split her time between the sick twin in hospital, the toddler and, of course, her husband. Whether at home or hospital she felt guilty. This seemed understandable but she felt it was neither understandable nor, indeed, forgivable. This was the message she was getting from her family and because the hospital was so far away she had to spend over half the week away from home. She also feared the hospital staff had "given up" on her baby because it was so premature and she felt her presence was necessary to keeping her baby alive.

For this mother the telephone was her only means of securing therapeutic support. She simply had no time to make visits elsewhere. We maintained regular weekly contact for 6 months when, against all odds, her baby came home, still very ill but they were at last together as a family. She sent me a lovely letter with photographs and I was particularly grateful for the useful feedback she gave me.

Sadly, about two months later my client's surviving twin died, quietly at home, and it was only then that she began to talk about the other twin.

She felt she had failed both her babies by letting them both die and was struggling through each day with a list of "if onlys". I knew little about the twin who had died in utero but six months later she was at last able to say "I killed my baby".

She had opted for a selective foetocide because the twin had a condition incompatible with life and medically it was felt that this was the best option for the "healthy baby".

This case emphasises the importance of not making assumptions. Otherwise this client may never have

been able to share her burden. By showing respect for her process and not being judgemental about what they choose to tell, or not tell, we enable clients to share their worst fears and sometime more readily than if we met face to face.

The Making of a Memento

Joy Cuff¹⁰

As a painter and calligrapher I have worked with bereaved parents for several years to create paintings, drawings or calligraphic cards with personal inscriptions and poems, often composed by the bereaved parents themselves. As an artist I strive to interpret the ideas and memories of bereaved parents to commemorate the loss of a baby, babies or child in a form which can be seen as a celebration of the memory of that child.

No photograph may have been taken but a memento, perhaps of the family group, can be painted or drawn. Often it is only some time after the loss of a child that thought is given to how best the memory can be preserved. Parents have told me that it is comforting to portray their surviving twin with their lost brother or sister, especially when the composition and colours are sensitive. Siblings also take great comfort in seeing this delicate portrayal.

Working very closely with the parents, I can gently add or change aspects of the painting. For instance some stillborn children are 'dressed specially' for the photograph, some with hats and mittens on to hide a deformity. Parents can be very upset by these original images but colours or features can be changed and special elements added, such as a particular shawl, toy or cot detail.

Paintings may take many months working closely with the parents and in one case the whole family. But sometimes a painting is "just right" in quite a short time. The painting is only finished when the parents feel it records the special memory they wish to share with friends and relatives.

The whole process has been seen by some as part of their healing. One bereaved parent told me that to have a painting of their lost child was the final "coming to terms with their loss".

A painting cannot replace precious photographs, but photographer and artist can work side by side. So often the photographs are taken in haste and in harsh hospital lighting, so that parents feel they must be hidden away, and not displayed outside the family.

It may take many months or even years for bereaved parents to be able to decide if the creation of a special memento is appropriate for their lost child or twins. One mother wrote in the Tamba newsletter¹ that 'It was the best thing I ever did as it helped me to come to terms with my loss. Having them on my wall acknowledged the fact that they did exist and were part of my life and still are.'

1. Tamba Newsletter. April 2000

See page 248 for a colour reproduction of one of Joy Cuff's paintings.

Beginning in York...

Abelone Glahn¹¹

Two years ago I visited a Waterfront Bookstore in York, England and started looking for books on twins as I do every time I am abroad. On one of the shelves I found Joan Woodward's book *Lone Twin*. But unfortunately I realized, that I hadn't brought enough money, so I handed the book to the shopkeeper asking her to guard it, while I exchanged money in the nearest bank. When I returned,

I found her totally lost in reading the book.

I was somewhat surprised and she apologized for studying "my" book and then said:

My older sister was born a twin, but her sister died during birth. My sister didn't know until my mother told her recently, on her 38th birthday. Now I understand the way she has behaved, and why she always felt lonely.

I got the book and was on my way out, when she looked very closely at me and added: "And maybe I wouldn't have been born, if the twin had survived..."

That very day I understood that losing your twin is not only an issue for the lone twin but for the whole family. Furthermore I suddenly faced the unspoken fact, that I as a mother of twins could myself someday lose one of my sons.

I later invited Joan Woodward to lecture in Copenhagen and in March 2001 she and Irene Coppock gave two most extraordinary lectures, one for professionals, one for lone twins.

Out of this has developed a net-work within Denmark already consisting of over 20 lone twins, who meet every six months. And now, as the founder of Nordic Twinnet I am more than pleased to have enlarged its scope to include this new organization. ■

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