



Child Bereavement Support
(Singapore)

Farewell, My Child

Stories told and
memories cherished:
shared experiences of
child bereavement





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Dedicated to our children
dearly loved and deeply missed

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Petals

Life is a stream
On which we strew
Petal by petal the flower of our heart;
The end lost in dream,
They float past our view,
We only watch their glad, early start.

Freighted with hope,
Crimsoned with joy,
We scatter the leaves of our opening rose;
Their widening scope,
Their distant employ,
We never shall know. And the stream as it flows

Sweeps them away,
Each one is gone
Ever beyond into infinite ways.
We alone stay
While years hurry on,
The flower fared forth, though its fragrance still stays.

– Amy Lowell

FOREWORD

Sonya Szpojnarowicz
President
Child Bereavement Support (Singapore)

The love a parent has for a child can be enormous, overwhelming and life changing. When I first became a mother, on 5th May 2000, I felt such a surge of joy and pride. The world seemed like a new, miraculous place—I felt reinvented, a bigger, better and more confident person. I felt that I could and would make everything good for my child, nurture him, sort out any problems, deal with anything, fix anything, pour endless and unconditional love into his little world and make him the best, happiest and strongest person possible.

When my first son died, nearly two years later, my world collapsed around me. My confidence was shattered, my joy vanished. I felt as if I had been hurled into a new universe, one that was frightening, bleak and unfamiliar. I couldn't imagine how I was going to keep living.

Not long after Max's death, I met a "befriender" through the UK cot death support organisation (Foundation for the Study of Infant Death, or FSID), whose daughter had died in similar circumstances about 28 years ago. She showed me a beautiful family photograph—a picture of her and her husband surrounded by their other daughters, their sons-in-law and a new grandchild, everybody happy and laughing. She called this her "light at the end of the tunnel" photograph.....

She made me believe—and hope—that I **COULD** keep living, and that one day I might be able to laugh again too.

Grief is a long and tortuous journey, an exhaustingly steep and rocky mountain path that sometimes seems impassable. Each of us who loses a child has to walk this road in our own way and in our own time. But we are not alone. Many have walked this road before us, and others are walking along with us—and a helping hand from a fellow traveller can make an enormous difference.

Child Bereavement Support (Singapore) hopes to provide such a helping hand. We have all had our lives turned upside down by the overwhelming, terrible loss of our beloved child. None of us will ever be the same as we were before. We all live with the pain of missing our children, what they were, and what we hoped for their futures, and we live with the awful knowledge of how powerless we are and how fragile our lives are. But we have not lost hope—we are still living, finding our own ways to bring joy and meaning back into our lives.

In this book we share some of our stories, telling of our beloved lost children and how they died. We also share our experiences of grief, and of how we have managed to survive. We want to bring support and comfort to all bereaved parents here in Singapore and to help them believe that there IS light at the end of the tunnel.

Mother and Child

A child is a blessing
A gift from above
Oh happy the parent
With children to love.

Then forms a bond
Not easily broken
Love it is silent
No need to be spoken.

Each child is tended
With kindness and care
Deep is the love
The family share.

Parents and children
Love strong and sure
Will bind them together
And last ever more.

– written by a student of Helen Bradford,
Sonya's mother, who was an English
teacher

THE CHILD BEREAVEMENT TRUST (UK)

Jenni Thomas, OBE
Founder and President
The Child Bereavement Trust

It was only when I trained as a counsellor in 1980 that I began to understand my own childhood experience of loss and bereavement. I became aware that the death of my father during the war when I was two, had affected me in many ways. Obviously I do not remember him, but the effect of growing up in a family where my Mother was grieving deeply, not only for him but also for her only brother who had been killed a few months earlier, stayed with me. I understand now that our family was in mourning during my childhood; two very important members had died and the space they left was enormous. I don't remember ever talking about feelings as a child, I can only recall overwhelming sadness that I didn't understand at the time. I do remember very much wanting to make it better for my Mother. I think that was where the taking care of people started, where the carer in me began.

The other revelation of my counselling training was that, having spent many years working in hospitals looking after dying babies and children, I had never thought of myself as bereaved, a bereaved child. I had no training in understanding loss and grief as a healthcare professional. We were just expected to know how to deal with death, with distress. After all we were nurses, we must be good at it! No one I worked with, even the doctors, had any training in bereavement and most professionals felt hugely inadequate. All we had was our caring and humanity. In those days it was not considered professional to show any emotion. We had to appear untouched by the death of a child or we were not professional!

In truth, I noticed that the families appreciated staff who were able to show feelings and say how sorry they were that a precious child had died. The staff who distanced themselves and appeared unfeeling made it harder for families; yet they were often the professionals who had experienced difficulties in their personal life and were afraid to look at the effect this was having on them and their work. I wanted to do counselling

training to help me understand people, and in many ways it did—but most of all it taught me about myself, and why I was drawn to bereavement work. This new awareness left me questioning the whole culture within the UK healthcare system.

The biggest problem for healthcare professionals generally is that it is not seen as a strength to need support in our working lives. Even when a patient dies, if we show distress very often we become the casualty in managers' eyes! I believe it should be a fundamental part of every professional carer's training to develop self-awareness, and recognise when we ourselves need support. It is a strength to ask for support, not a weakness. We need to be encouraged to look at ourselves and to be self-aware, to consider what may have led us to train as doctors or nurses, and to enable us to give the best possible care to bereaved families.

For far too long, the emphasis has been on the technical success of medical treatment—yet we cannot separate medical care and emotional care. They are both fundamental to our well-being. My quest to change the system began its long journey—death and dying had to be acknowledged as important areas for all healthcare professionals.

Following on from my counselling training, I had to negotiate with senior management how I could provide bereavement counselling for families. This was indeed pioneering work with many obstacles to be overcome! I began by counselling parents whose infants had died on the neonatal unit or in maternity soon after birth. My manager had the vision to see this was something the parents valued and encouraged me to establish a bereavement service within the hospital.

This significant step has led to much more. In 1994 I founded The Child Bereavement Trust, a national UK charity that would take this much-needed work forward. The Charity's aim is two-fold: to train and support professionals in bereavement, based firmly on what families have taught us, and to educate and work with policy makers across the statutory and voluntary sectors. In 2002 I was honoured with the title "OBE" (Order of the British Empire) for my work with the Charity. The Chief Executive is Ann Chalmers, with whom I have worked for many years in this field.

We are proud to have an association with our first international support group—Child Bereavement Support (Singapore). My niece Amy Fennell, on arrival in Singapore in 2003, fundraised to provide help from The Child Bereavement Trust to families locally. Amy invited me on a lecture tour in Singapore and I met the five bereaved mothers who have founded this important Charity in April 2004. I was deeply touched by their courage in their shared sorrow, and by their determination to DO something to improve the situation in Singapore. We look forward to continuing to work with CBS to provide training to healthcare professionals in Singapore, and we fully support their work to build a network of bereaved parents in Singapore and to share information, advice and support.

A PERSONAL JOURNEY

Dr Lim Sok Bee

*Senior Consultant and Head of Neonatology Department
KK Women's and Children's Hospital*

The genesis of Child Bereavement Support (Singapore) (CBS) has been personally inspiring for me; the idea of a group of parents coping with the loss of their own child yet reaching out to others in need is selfless and heartwarming. Only a few months as a formal group, it has already grown in strength, gathering support from parents and healthcare professionals.

KKH manages approximately 14,000 deliveries annually, comprising a third of the total deliveries in Singapore. As a paediatrician at KKH for the past 14 years, I have had the pleasure of welcoming numerous newborn babies and caring for them. But I have also seen the grief and despair amongst parents who lose their precious children. There are about 70 deaths among children a year, including as many as 40 stillbirths. This is dramatic and painful, especially for a small island such as ours.

Several events in my life have led me to realise the need for hospital support for bereaved parents. In 1983, when I was on sabbatical in Melbourne, I had the privilege to work with extraordinary nursing sisters who worked tirelessly with parents and babies. Their care and concern for bereaved parents made a deep impression on me. In Singapore, I remember a syndromic baby girl (with abnormalities) who stayed at the hospital for about six months. We journeyed together with her parents, who were not Singaporean, through several surgeries and difficult moments. Finally, the doctors and her parents made the painful decision to withdraw intensive care support. Gently her mother held her baby in her arms, singing softly to her, "You are my sunshine". This changed my world.

It has been some 10 years since a group of dedicated nurses and I started to provide some form of organised support for bereaved parents in their time of grief. We realised that grieving for a lost child was necessary and universal, regardless of race or creed. Cultural and religious practices differentiated its form and expression, but by and large, grieving was a most natural part of living.

Unfortunately, most Asians grieve silently and alone as they mostly feel inhibited or

have no one to turn to. We noticed that many bereaved parents find comfort in meeting someone who understands their tragedy and who allows them to express their sorrow and misery. Our nurses spontaneously played this role and our initial efforts to bring comfort to hopeless parents were done on a “volunteer” basis. Two years ago, a formalised care giving service for bereaved parents was proposed. We now have a nurse coordinator whose role is to provide support for bereaved parents and to train personnel helping bereaved parents manage their grief.

It was timely in August 2003, to receive a call from Amy Fennell, an English expatriate living in Singapore. Her aunt, Jenni Thomas, founder of The Child Bereavement Trust (UK) (CBT) was then available to provide training for medical professionals in bereavement support. For the group of us in KKH, struggling to provide support for bereaved parents, this piece of news could not have come at a better time.

In April 2004, Jenni conducted lectures and workshops on bereavement support, involving doctors, nurses and medical social workers from all hospitals in Singapore. We invited staff of various organisations like the Assisi Home and Hospice and the Children’s Cancer Foundation. The feedback pointed to Singapore’s great need for training in this area.

Besides benefiting from Jenni’s excellent teaching and wealth of experience, I also had the privilege during her visit to be introduced to a small group of bereaved mothers here in Singapore. Since that initial meeting, we have continued to meet as a group to sow the seeds of founding CBS.

I must acknowledge this group of very courageous and motivated mothers who never cease to inspire me as I attempt to establish bereavement support services for all hospitals in Singapore.

Through their pain and tears over the months, each one is determined to reach out and help other bereaved parents. I salute their tremendous effort and noble intentions.

With CBS firmly entrenched, our plans for developing services in the area of bereavement support will no doubt materialise. We aim to give support to bereaved parents through working with CBS. Together we could plan memorial services for parents and families to remember their beloved little child, and conduct monthly support group meetings for all.

We also hope to train volunteers and professionals such as nurses and doctors at all private and restructured hospitals in Singapore. We believe that hospitals should provide bereavement support as part of their overall services. This could be in the form of a special room for care and counselling or provision of a memory kit for the parent’s keeping (eg footprints of stillborn babies).

We intend to make accessible materials available for bereaved parents from CBT (UK) and develop our website with pertinent information for parents in need.

I hope you will lend support to CBS and their very worthwhile cause, and assist us in providing the much needed support to parents who have had to bid farewell too soon to their precious children.

A MESSAGE FROM NKF CHILDREN'S MEDICAL FUND

Dr Jeremy Lim

*Head, Department of Medical Affairs and Planning
National Kidney Foundation*

Losing a child is one of the most difficult things a person can experience. The pain and sorrow is often compounded by a deep sense of isolation and the inevitable questions that echo through a silent night while the world is sleeping, “Why did this happen?” and, “How can my life go on?” These must be addressed as the long journey to normalcy while honouring the memories begins, but it is a path that need not be walked alone.

Child Bereavement Support (Singapore) was set up to support bereaved families and to educate healthcare professionals to “deal more compassionately with bereaved families and with a greater understanding”. The book you have in your hands marks the first step in their mission and shares the stories of remarkable parents and caregivers as well as providing very practical and useful information to families in difficult times.

We in the NKF Children’s Medical Fund offer a number of programmes to improve the plight of sick children and their families, and while we support the children in life, we cannot abandon their families in death, and thus it is fitting that our energies and resources are also focused on facilitating the work of Child Bereavement Support (Singapore).

It is with a profound sense of honour and privilege that I pen these words of behalf of this group of courageous men and women who have banded together for a common social cause. The American anthropologist Margaret Mead once said, “Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.” We are proud to support the efforts of Child Bereavement Support (Singapore) and congratulate them on the launch of the group and this book. We wish them every success in their endeavours.

CHILD BEREAVEMENT SUPPORT (SINGAPORE)

HOW WE BEGAN

Sonya Szpojnarowicz
President
Child Bereavement Support (Singapore)

The loss of a beloved child is something that most parents can hardly bear even to think about, and cannot begin to understand. Bereaved parents who have been through this nightmare, and have had to learn to live with this enormous feeling of loss and sadness, share a special bond of understanding.

Child Bereavement Support (Singapore) (CBS) started out as a small group of bereaved mothers, realising that there was no formal support network in place in Singapore, and that there was a great need for something like this. Some of us knew each other already, but we got together as a group as a result of a visit to Singapore in April 2004 of the founder of The Child Bereavement Trust (CBT) in the UK, Jenni Thomas. When we met we immediately felt the strong and special bond that we all shared in our terrible experiences of losing our children, and as we talked about CBT we felt inspired to try to start something here in Singapore.

The original five mothers who met that day in April were Sonya, Marina, Stefanie, Trish and Susie. Our experiences were very different, but we shared an important bond. The stories of our lost children are included in this book. Along the way we have met many other bereaved parents—from a variety of racial, religious and cultural backgrounds. We are united in our sorrow and pain and yearning for our children, but also in our desire to help each other by sharing our different experiences as we struggle along our individual journeys of grief.

Traditionally, the culture in Singapore has not encouraged emotional support or discussion on bereavement, especially child bereavement, and people often find it difficult to talk about such things. As a result, many bereaved families find they have no one to turn to and no one to help them in their most desperate time of need. Those of us who lost our children here in Singapore found that an already terrible situation was horribly

exacerbated by a lack of understanding, respect and compassion among various professions we encountered during our bereavement. And we were all desperate to find someone who might understand, someone who had been through a similar experience, and was willing to lend support.

We have all found that meeting other bereaved parents is what has made the biggest difference to us, and given us the most support, the most hope and the most comfort. And so in honour of our beloved lost children we have set up Child Bereavement Support (Singapore) as a charitable society registered in October 2004. CBS will offer support to everyone in Singapore who loses a child—no matter how recently or how long ago or in what circumstances. We are holding regular open support meetings, and will offer friendship, support and information through our website. There will be a database of bereaved families in Singapore so that we can help match up appropriate “befrienders” to newly bereaved parents (as organisations like FSID (Foundation for the Study of Infant Death) and the Compassionate Friends do in the UK). This has already been happening on an informal basis as word of our society spreads fast. We are gathering resources, compiling recommendations and advice, and building a library.

The main aims of CBS are two-fold—as well as supporting bereaved families here in Singapore, our second (and equally important) aim is to provide education and information to the medical and caring professions here to enable them to deal more compassionately with bereaved families and with a greater understanding. One of our founder members is Dr. Lim Sok Bee, Senior Consultant and Head of the Neonatology Department at KK Hospital, and she has already been pivotal in arranging training of medical professionals in conjunction with CBT (UK), and more training sessions are planned. We are also fortunate in having the support of the Children’s Medical Fund under the National Kidney Foundation who will work with us in achieving this aim. Some of us in our network have had unfortunate experiences with doctors, nurses, coroners and mortuary staff, and police, where their lack of compassion served to add yet more pain to our nightmarish experience. We want to work to promote “best practice” in bereavement support, so that we can improve the situation for others in the future. A caring professional can make all the difference.

We all hope that CBS will be able to make a positive difference to help all parents who lose a child here in Singapore—whether that child was still inside his mother’s womb, in early infancy, at any stage of childhood or even into adulthood. Nothing can take away the pain of such loss, but the sharing of support, compassion and understanding can help lessen the load.

Those whom we have loved
Never really leave us.
They live on forever in our hearts,
And cast their radiant light
Onto our every shadow

– Sylvana Rossetti

FAREWELL, MY CHILD

Bereavement turns your world into disarray and leaves you in shock facing anger, bitterness, despair and confusion. We will all experience the loss of a loved one in our lifetime but the loss of a child is a parent's worst fear. To outlive one's child is tragic yet it is an agonising ordeal that many are forced to face.

A woman treasures her first pregnancy and relishes her metamorphosis from wife to mother. Devastatingly she then gives birth to a baby who doesn't remain in her world to share in her dreams. She is enveloped with sadness and grief.

A family attends a party and both sons engage in twilight games with their friends by a pool. Suddenly the calm is shattered when a tiny body is discovered floating in the water. Days later in a hospital the family must come to terms with their four-year-old's death and submit to their sorrow.

A mother watches her toddler quietly play with a touch of fever and a little cold. Never could she imagine the imminence of an emergency ward, the tubes needed to keep her baby breathing, and the eventual letting go as she painfully allows her daughter to slip away.

A daddy never experiences the joy of having his son at home, to cuddle, tickle and throw in the air. Yet he visits him daily for the full nine months that his "little man" manages bravely to struggle on.

A mother can only observe as her teenage daughter determinedly follows her dream. Her body slowly destructs and the strength of her mental determination is unable to secure her future. Another mother buries her own child.

Such stories can tear you apart. They can be exhausting, consuming and fill you with fear. For those grieving it often helps to share the memories, to ease the pain and to keep a picture alive. For others it may be important to hear that they are not alone.



Alexandra

Alexandra Wigley
26 – 31 March 2000

Marina and Charles are English expatriates who have lived in Singapore for four years. It was while living in Australia that they conceived their first child, Alexandra. It was a normal, healthy pregnancy and they were happily looking forward to becoming parents for the first time. But things started to go wrong during Alexandra's delivery—she suffered distress and meconium aspiration—and then lived for only five days in Intensive Care. Marina recounts their tragic journey.

Written by Marina Parker, Alexandra's mother

I will never, ever forget the last appointment I had with my obstetrician—four days short of my 40-week due date. After examining the baby and declaring that all was well (as it had been for the entire duration of the pregnancy) and in place for birth, he jokingly turned to me and said, “Try not to have the baby this weekend as I am going away on a golfing weekend”. Words that will haunt me for as long as I live.

Exactly four days later, on Sunday morning, I went into labour. Contractions were slow and infrequent and so I was told to stay at home until they were less than five minutes apart. My husband and I spent the day in a mood of great excitement mixed with nerves and worry about the birth.

Eventually, at about 5.00 pm, when the contractions were coming thick and fast, we decided to go to the hospital. On the advice of many friends, we had chosen one of the most exclusive, private maternity hospitals in the city, but when we arrived it seemed unnervingly quiet and dark. It turned out that not many women were in labour that

night and because my obstetrician was still away, the locum would be delivering my baby. The whole maternity unit felt as if it was operating on half steam.

We were admitted to the delivery room where I was told to make myself comfortable. Contractions were still about five minutes apart, painful but manageable. The midwife examined me and told me I was about three centimetres dilated. We were then left for a considerable amount of time just to labour on alone. Contractions became increasingly more painful, and finally I was offered pethidine, which I took without hesitation. I had to lie down for this and again time seemed to pass endlessly while I was breathing in the gas and dealing with the pain. The midwife eventually put me on the heart monitor and started to trace the baby's heartbeat. My husband and I thought nothing of this machine strapped to my tummy and again, a lot of time seemed to pass with nothing really happening.

The midwife came in and out to check the trace and then the last time she read it, some two or so hours into labour, panic came across her face. "This doesn't look right" she said and told us she was going to call the doctor in straight away—he was at home at the time.

When the stand-in obstetrician arrived, he looked at the trace silently and then checked to see how dilated I was—still he said nothing. I sensed that something might be wrong but was still at the mercy of the professionals to tell me what was happening. Naively, of course, I assumed that in their hands, all would be well. The doctor told the midwife (not me) that I was eight centimetres dilated, the trace was a bit flat but to keep me labouring. He further ordered that I be given an epidural to speed things along. Not too long after he left, the midwife looked really concerned and she blurted out, "I am over-ruling him. This baby needs to come out. We need to do a C-section straight away" and she ran out of the room.

Alone with my husband, we both began to panic. What was happening? Was it going to be ok? He kept holding my hand, reassuring me and I remember staring blankly up at the ceiling, breathing in gas as a strange sense of foreboding crept over me. The midwife and several others rushed back in and explained that I had to have an emergency caesarian. However, we would have to wait for the anesthetist to come and administer an epidural (he was busy with another operation) and that they had contacted my obstetrician who was racing back from his golfing weekend. At this point, I knew something was terribly wrong but again assumed that they would deliver the baby without trouble. It seemed like an age before the anesthetist eventually arrived and then it was all go—in a haze of voices, action, needles, I was prepared for a C-section and rushed along corridors and down to surgery.

My obstetrician appeared, gowned up, and he performed the C-section. He didn't say a word to me. The anesthetist was holding one of my hands and stroking me saying, "It's all right, it's all right." Charles was holding my other hand with a look of sheer terror on his face. The quiet was unnerving and after much tugging and pulling in my stomach,

the obstetrician held up a grey, lifeless baby declaring, "It's a girl." We heard no crying, no sound whatsoever. She was taken away immediately to be resuscitated and that was the last we saw of our new daughter for the next twelve hours.

The obstetrician finished the surgery and said that someone would come and see us very soon to tell us what was happening. He explained that Alexandra was very sick and had to go to special care. The midwife asked us what her name was and stroked my head in sympathy. Charles and I were simply in total shock.

Silently, I was wheeled away to my room on the maternity ward where Charles and I were left alone to cry and scream. I could hear newborn babies in the adjacent rooms and the pain was no less than if someone just came and put a knife in my heart. A midwife intermittently came to tell us that someone would come soon to see us but we couldn't go and see our baby.

Eventually, a team of professionals arrived in our room and gathered round my bed. The obstetrician just looked forlorn and lost and said very little. The pediatrician explained very matter of factly that Alexandra was very, very sick. She had lost a lot of oxygen during the birth, had got into distress and swallowed meconium into her lungs and stomach. They had pumped as much as possible out but she was in a critical condition and had most certainly suffered brain damage, the extent of which they could not tell us. But the pediatrician reiterated that it was very serious indeed. The next blow was to hear that she urgently needed to go to a better intensive care unit but no place could be found for her in the city hospitals. At this point they would have to helicopter her to a hospital about two hours out of town.

The nightmare continued into the night as we listened to the newborn babies variously crying and waited for news of ours. A crib had finally been found for her in one of the major public hospitals in the city and they were to transfer her that night. We were only allowed to follow the next day because I had had a caesarian. One tiny moment of kindness came when the same midwife who had realised that something was wrong during labour came and gave me a Polaroid picture of our beautiful baby girl that she had taken. I clung on to it all night looking at my little girl with her olive skin and dark mop of hair, attached to a hundred tubes and wires. We cried and howled all night at what had happened and that we didn't have our little girl with us.

For the following week, we were placed in a private room at the public hospital and spent our days in intensive care willing our little girl to live. If by some miracle she did survive, we were facing the fact that she would be severely handicapped. No one told us during that time what the real prognosis was and we faced setback after setback as she began to have fits, was unable to pass urine on her own and then finally gave up drinking the milk that I had been expressing for her. My family came immediately from the UK and sat with us day and night. Friends did not know whether to congratulate us on the birth of our daughter or commiserate. Few except the very brave dared come and see us.

On Thursday 30th March the results of Alexandra's brain scan came back. We were

asked to meet with the pediatrician in our room. His face said it all. She was completely brain-dead and would never be able to breathe without a ventilator. He recommended that we take her out of intensive care and let her die. We prepared for this the next day. A truly horrific, unbelievable thing for any parent to go through.

On Friday 31st March, 2000, our five-day-old baby daughter was taken out of intensive care. She spent eight amazing but also devastating hours with us alive as we just held her and kissed her and said our goodbyes. She took her last breath in my arms and I watched her die. My beautiful angel girl. We spent the entire night with her under the guidance of one of the nurses. Together we bathed her, took her footprints, handprints and lock of hair, put her in her special little dress, wrapped her in a beautiful muslin wrap, gave her a teddy and sent her on to heaven. For that night I am truly grateful.

The six months after Alexandra died were the most horrific of my entire life. With her death, I had lost all sense of purpose and truly felt that I no longer wanted to go on. Four weeks after her funeral, I finally gave up the strength to carry on and entered the first stage of what professionals called post traumatic stress disorder—a full-on nervous breakdown. I spent the following six weeks in a psychiatric hospital drugged up to the eyeballs with anti-depressants and sedatives. Thanks to my darling, darling husband, my parents, an amazing grief counsellor and some incredible friends, I eventually got out of there, came off the drugs completely, left our old life far behind us and started a new one—just the two of us.

Four and a half years later I gave birth to Felix and Luca—Alexandra's twin brothers.

Dreamland (excerpt)

She cannot see the grain
Ripening on hill and plain;
She cannot feel the rain
Upon her hand.
Rest, rest, for evermore
Upon a mossy shore;
Rest, rest at the heart's core
Till time shall cease:
Sleep that no pain shall wake;
Night that no morn shall break
Till joy shall overtake
Her perfect peace.

– Christina Rossetti



Alistair

Alistair John Grawert
19 May 1989 – 15 March 2004

Anne and Helmut are German/Australian expatriates who have lived in Singapore for 10 years. The bottom fell out of their world when their youngest son Alistair suddenly died, peacefully, in his sleep, having shown no signs of any illness. One year on, the family miss him terribly and are still in a state of shock.

Written by Sonya Szpojnarowicz, from an interview with Anne Grawert, Alistair's mother

At 14, Alistair was still the baby of his family, much loved by his parents and his older brother and sister Christopher and Yvonne. As the others had left home, he was the only baby left in the nest and he was the centre of his parents' world. He was a happy, intelligent boy with a tremendous sense of humour, who exuded a quiet confidence and inner strength. He had a full and happy life, and loved his school, his pet cat and his tennis, as well as going for long walks in beautiful surroundings such as Sungei Buloh with his father Helmut.

On Sunday 14th March 2004, he enjoyed a peaceful, quiet day with his parents. He played tennis as usual at Alexandra Park, and felt a little tired and unwell after the exertion—but after taking a shower back at home he felt fine again, in fact so fine that he ate a whole pizza for his dinner. He had a chat on the phone with his brother Christopher and went to bed as normal.

The following day was Anne and Helmut's 30th wedding anniversary. The day started

just like any normal day, and they talked about what they might do that evening to celebrate. Anne went downstairs for her early morning coffee, then went up to wake Alistair as usual and help him get ready for school (his uniform was already laid out for him in his brother's room). She opened the door—loudly—as she always did, and turned off the aircon. But there was no answering grunt from Alistair. She opened the curtains, and saw that he was lying face down (as he always did) and still. Thinking he must be in a very deep sleep, she talked more loudly to him, and began to feel a rising sense of unease. Something wasn't quite right. She ruffled his hair—nothing. She tried to pick him up and shake him, feeling confused and panicky. This must be some silly joke of Alistair's. But she began to feel that it wasn't funny any more. She turned him over, feeling almost angry with him for not responding—but saw that his face looked abnormally mottled and blue around his mouth.

In that split second of shock and horror, Anne could only grasp that something was terribly, terribly wrong. She screamed for Helmut, who rushed in and shouted, "Call an ambulance!" He knew immediately that his beloved youngest son was dead—but Anne was in such shock that she just couldn't take this in. She ran to the security gates at the condo, to tell them to open the gates as an ambulance was coming, screaming, "My boy won't wake up; he WON'T wake up! Somebody help me!"

Even when she went back to Alistair's room, now already full of people trying to help, she still couldn't feel anything except shock and panic. She was sure he was still going to wake up and open his eyes—she was convinced she could see his eyelashes moving—but they were only fluttering in the breeze from the fan that someone had turned on.

Everything else passed in a horrible blur, and Anne remembers little. She remembers their part time cleaner arriving in the midst of the chaos and confusion, the friendly security guard crying, the police checking Alistair's room, a neighbour who was a nurse doing CPR—and most of all she remembers lying in bed holding her beloved boy close to her, not knowing what else to do. After his body was taken to the mortuary she only remembers wanting desperately to sleep, to escape from this unbelievable nightmare, to wake and find everything all right after all. She still felt all that day that he would walk in through the door, that it was all a big mistake.

Everybody was in a state of extreme shock. How could a healthy 14 year old boy just die in his sleep—with no warning, no symptoms of any illness, no sound? It could not be happening. The whole family was turned upside down. Alistair's brother and sister, who were both working overseas, hurried back to the family home in Singapore, and they clung together in their grief and shock, surrounded by loving friends (also reeling in shock and disbelief).

Alistair's body was brought home for the week before his funeral, and the apartment was bursting with flowers. Anne feels glad that they had this time to be with him in their own home—particularly as they never had a chance to say goodbye to him before he died. A kind and compassionate man from the funeral directors suggested that they might

like to put special things of Alistair's inside the coffin with him—and she is grateful for his thoughtfulness, and glad that they did this.

The autopsy concluded that Alistair had died of “acute myocarditis”—a “normal” virus had suddenly attacked his heart, and he would have died instantly. No symptoms could ever have been seen, and nothing could ever have been done to prevent it.

The family struggle to carry on with their lives, and Yvonne has moved back to Singapore to be with her parents in their family home. Anne and Helmut feel lost without their youngest son, and are both exhausted from keeping up the appearance of coping. But the family will all be together to mark the first anniversary of Alistair's death, to share the grief they all feel so acutely.

Eulogy: To Alistair

Written by Helmut Grawert, Alistair's father

Alistair was a very special person.

At funerals, people are often described as wonderful people—after all, who wants to say anything negative about someone who has died?

But this is different.

Alistair does not need to be described as a wonderful person—he simply WAS wonderful.

Yes, he often withdrew into his own world. He was a very private person. To those he loved, he showed his love in a very shy and non intrusive way. Sometimes almost unnoticeable. Even as an almost 15 year old, he would suddenly come, put his arms around me and say, “Papa, I love you.” Normally teenagers at that age fight with their parents.

He very much loved his mother, who was the real centre of his life, as I travelled so much. He loved his sister Yvonne, his brother Christopher and many other people. But only to a few chosen ones did he really open up.

When his closest friend at school, Martin, left, he wrote a little letter which said, “I am so sad that my best friend left, but I am so happy for him, that he is now back with his parents and siblings.” It was important to him that other people were happy.

When Yvonne left for Australia, and Christopher soon after for Germany, he was so sad—but he accepted it without complaining. He just said that he would like always to be with us.

He was very modest and undemanding. If you wanted to buy him something, he would choose something cheap, or say, “I don't want it, it's

too expensive.” He refused pocket money, stating, “You give me everything I need.” Of the money we gave him for his school trip to Thailand, he only spent 10 baht!

Alistair loved animals, and he decided to become a vegetarian at the age of 10. He said, “I don’t want animals to die for me.” It was his decision and he stuck to it.

He was incredibly adult in his views from an early age. He did not speak often, preferring to listen to other people. If he said something, it was often very smart and sometimes very witty.

He liked his tennis very much, and was getting quite good at it. He was a good swimmer, and sometimes came along with me to play golf. He did not like it as much as tennis and sometimes, I think, he just came along to please me.

When he recently did quite well in a tennis tournament, I asked him later when he came home, “How did it go?” He replied, “Oh, quite OK.” My wife, who came in after him, then told me that he had made it to the semi finals in singles, and had actually won the doubles together with his partner. I would have boasted about this to everyone—he was just very modest about it.

Alistair was never mischievous. He was always straight and honest.

He felt deeply for people, but found it difficult to open himself up and show it. I am sure that there are many among you whom he loved more than you might realise.

Alistair died in his sleep at about 4.00 am on March 15th. The cause is still mysterious as the autopsy showed him to be in good health, only with some indication of a viral infection.

His face was very peaceful and he looked like someone quietly asleep.

He went as quietly as he lived.

We would have loved to have him around for the rest of our lives.

But it was not to be.

He is always deeply engraved in our hearts and thus will always be with us.



Annika

Annika Force
19 August 2004

Mala and Darrin are American expatriates who have lived in Singapore for three years. They were delighted when they conceived their first child. But a routine check-up almost at the end of Mala's pregnancy turned into a nightmare when Annika's heartbeat could not be found.

Written by Darrin Force, Annika's father

After an entirely uneventful, normal pregnancy, we lost Annika, our first baby, four days before her expected due date of 22nd August, 2004. One week earlier, we had seen our obstetrician for what we thought would be our final prenatal checkup. As with every other visit, things were just fine. Our doctor anticipated that labour would begin within no more than two weeks.

At our next checkup on the following Tuesday, Mala's routine exam began with the familiar fetal monitoring she had been receiving throughout the later part of her pregnancy. After several attempts to find a heartbeat, the nurse called in the doctor, who immediately ordered an ultrasound, and called for me. After repeated attempts to establish a heartbeat, it was clear that our baby had passed away. The utter shock of this instant in time, when every hope, dream and plan we had was irrevocably erased, will be forever etched into our memories.

This was supposed to be the time when we would be rushing to the hospital to start

the labour process, witnessing the birth of our child with a mix of pride, joy, and awe. We were supposed to be enjoying the first few moments of life of a precious little boy or girl. We were supposed to be making the happy phone calls to expectant relatives and friends. Instead, we were faced with decisions that no new parent's darkest nightmare would conjure.

We were lucky in that our doctor couldn't have been more compassionate and supportive. After confirming and reconfirming that our baby was indeed gone, her next action was to find a quiet room to just be with us. Seeing Mala in utter shock was very difficult for me, but our doctor's calm, steady and loving presence gave me the boost of strength that I would need to comfort my wife. Next, our doctor immediately called a grief counsellor who had also lost her baby at full term several years prior.

Within 40 minutes the grief counsellor was with us. Sharing our experience, she could relate first hand to our deep shock, pain and loss. With her calm, soothing presence and compassionate, caring advice, she helped us sort through some of the most important decisions we would face. First, and most important, was the decision to go through with a full delivery. Given the options of (a) immediate Caesarean section, (b) induced labour or (c) waiting for spontaneous labour, she counselled us to seriously consider going through a full delivery, as difficult as that sounded at the time. While an immediate Caesarean seemed the most expedient way to stanch our grief, we came to feel that a full delivery was the most appropriate way for us to honour our baby. It seemed to us that she deserved the privilege, attention and commitment of a full delivery, even in death.

So labour was induced and Annika was born the next morning at 9.00 am, on Wednesday, 19th August, 2004. She was a beautiful, 3.2 kg baby girl who had Mala's dark wavy hair and my lips and chin. She was perfectly normal, except that she wasn't awake.

The hospital staff were absolutely wonderful in their compassionate understanding of our need for time with our little baby. We held her for a long time, talking to her and trying to memorise every detail of how she looked and felt. We told her that we loved her, that we knew she was in a good place, and then, after nearly three hours, it was time to say the most difficult goodbye either of us had ever said. If anything, we now wish we had spent more time and taken more photos than we did. For us, this was our chance to finally meet her after waiting for so long. We got to see and enjoy all the unique physical features we had wondered about. We also felt that we were honouring her short life by affording her the respect and attention she deserved.

The following weeks were a blur of tears, anger and desperation as we pleaded with God to turn back time and bring Annika back to us. Then came the weeks of understanding that this had happened followed by slow acceptance. The support of our families and friends, combined with our own spirituality, allowed us finally to let Annika go.

The final autopsy results have ruled an inexplicable, sudden death. We hoped that

we would find some cause that would help us regain control and the ability to do something different next time. Instead, we are left wondering why this happened. We do take comfort in knowing that there is no medical reason which prevents us from having another child. It is this hope for the future that enables us to get through each day.

Not an hour passes where we don't think of Annika and how much we love her. Though she lived for a very short time, she has had an amazing impact on our lives. Her little life has forever changed us. She has brought us spirituality, an appreciation for those we love, and the joy of parenthood. Though she's not with us, she will always be our perfect little daughter.

COPING WITH LOSS AFTER ANNIKA'S DEATH FINDING COMFORT IN HINDU RITUALS

Annika's parents found great comfort in the Hindu traditions and rituals surrounding their daughter's death. Annika's mother Mala was raised a Hindu, and her father Darrin had a deep appreciation of Hindu philosophy, so after her death they consulted a Hindu priest (*pandit*) and decided to follow Hindu death rituals. Each ritual has a profound psychological and spiritual significance, which they found deeply consoling. Hindus hold that our souls are immortal, and must pass through many births and deaths, learning as they go, before finally merging with God. But due to their attachment to worldly life and the physical body, departed souls may linger in the earthly realm for some time after death. In order to help the soul move on, the remaining relatives must perform certain ceremonial rites.

Annika's father Darrin tells how these Hindu rituals were integral to their healing and search for comfort and peace:

Helping the soul on its journey

After coming home from the hospital, our first step to helping Annika's soul on its journey, and to helping us let her go, was setting up a small altar with her photo, some of her clothing, and an oil lamp that remained continuously lit for nine days. Each morning, Mala and I tended to the lamp, and ritually fed our baby by preparing a simple offering of milk mixed with honey and ghee (a form of clarified butter commonly used in Hindu rituals. It is revered as the essence of the cow's love for her calf). Caring for Annika in this way gave Mala and me real solace, comfort and a deep sense of peace when we needed it most during those first awful days. We both felt profound comfort and satisfaction from taking care of our daughter in this very intimate and unique way.

Cleansing and dressing her body

The next set of rituals surrounded cremation. Accompanied by our dear friend who had flown over from the States to be with us, we met the funeral director at the hospital for the preparation rituals. Following tradition, I bathed Annika with special herbal water, then dressed her in the suit she would have worn on her first trip home from the hospital. The funeral director and I then draped garlands of flowers over her body. Mala placed into her coffin a bottle of milk, a small stuffed animal, and a letter we had written to Annika. On the drive from the hospital morgue to the crematorium, I had the privilege of carrying Annika's open coffin on my lap. This was an indescribably significant time for me, one that I will always cherish. These few quiet minutes together with my daughter allowed me to tell her how much I loved her, tell her about all the things we would have done together, and wish her a speedy journey to her next destination. I felt my own grief and loss, but these were eclipsed by a sense of peace, knowing that Annika was on her way to where she needed to be.

Collecting her ashes, fulfilling a role

After waiting the prescribed time following the cremation, the next ritual involved gathering Annika's ashes. This is traditionally done by the wife's oldest brother, but I realised with perfect clarity that this was the last thing I would ever do for my daughter, so I felt very strongly that I wanted to do it. After being led into a small ash collection room I, with my own hands, carefully separated Annika's remains from the debris (small coffin nails, etc) in the cremation ashes. As morbid as this might seem to non-Hindus (or members of other religions following this practice), this was a profoundly peaceful experience for me. Any sense of repulsion or fear was overwhelmed by the feeling of doing my duty, of fulfilling my proper role in serving Annika. I can't adequately describe the sense of pure, quiet peace and rightness I felt as I tended to her final mortal needs.

Preparations for funeral

The next step was to plan for Annika's funeral and the release of her mortal remains. Hindu tradition dictates that this should be done into a natural body of water. Living in Singapore meant easy access to the ocean, so we chartered a boat and prepared for the funeral. Although Mala is of Indian heritage, she was born in Guyana and grew up mostly in the US, so speaks no Hindi or other Indian languages. This made communicating with the local *pandit* nearly impossible. But just at the right time, another beautiful soul, in the form of one of our dear friends, came to our aid to help translate and assist with the preparations.

Prayers

Based on our *pandit's* counsel, we went through a series of three separate but related ceremonial prayer sessions, called *pujas*. After ritually cleaning our home, and donning a set of new, white clothing, the first *puja* took place at 5.00 am at our apartment. This *puja* invoked the help of our departed relatives to help Annika on her journey. After preparing an elaborate offering consisting of various herbs, fruits and incense, the *pandit* chanted Vedic mantras (prayers to various gods) and made offering to a small camphor fire (*agni*). Both Mala and I were integral parts of the ceremony, variously making offerings, chanting the mantras, and performing other symbolic gestures, all intended to invoke a smooth, auspicious transition from this world to the next. Finally, the *pandit* passed through each room of our house, blessing them and symbolically setting the stage for a new beginning.

Offerings

Next, we travelled to the beach at sunrise for the second ceremony, which was intended to help Annika's soul feel at peace, and to show her that it was time to move on to her next destination. It was a beautiful, poignant ceremony rich with symbolic offerings. Part of it involved Mala making cakes of rice flour and milk to symbolically feed Annika and her departed relatives. We also offered bananas, grain and ghee to the ceremonial fire (*agni*), symbolising our release of her soul. At the conclusion, Mala and I gathered the offerings and walked them out to the sea. We disposed of our clothes, again symbolising our realisation that this chapter of our lives was at an end, and a new beginning was on the horizon.

Releasing her to nature

Following the *pujas*, we all boarded a boat, sailing across a calm sea, under a beautiful, bright sky, and stopped in a beautiful, peaceful spot. Mala and I placed Annika's ashes, some flowers, and a beautiful letter our very dear friend had written onto a small white cloth. We carefully rested the cloth on the water's surface, then watched as it slowly sank into the clear, blue water. Slowly but irrevocably, our daughter's mortal remains dispersed into eternity. Naturally, part of us was deeply sad over our loss, but that bright sun, the expansive blue sky, and the love of our friends and family heralded a new beginning.



“Baby Grace”

“Baby Grace”
8 January 2000

Grace’s parents (who do not wish to be named) were delighted to conceive Grace after two years of trying. But their joy turned to sorrow when the 20-week scan discovered serious defects. An amniocentesis confirmed that Grace suffered from “Edward syndrome”, a lethal chromosomal disorder, and doctors advised abortion. Strengthened by their strong Christian faith, the couple decided to continue with the pregnancy and give Grace a chance. Sadly, Grace was stillborn.

Written by Grace’s mother

After two years of marriage, my husband and I were wondering whether it was the stress of my hectic teaching job that was preventing me from conceiving. Then we went to USA for 2½ months for my husband’s job assignment, and after we came back, were overjoyed to discover I was pregnant. I began to prepare for my baby’s arrival.

Then I went for my detailed scan during the fifth month of my pregnancy. The scan showed several defects—she had a cyst in her head and a hole in her heart. Her last finger was short of one phalanx and she had only one umbilical artery (the artery which transports food to the foetus) instead of two. Our gynaecologist immediately asked for an amniocentesis test, which had to be taken another day. During the course of this time, we prayed to God that He would heal our baby and that all would be well.

But the amniocentesis test confirmed our greatest fears. It confirmed that she suffered from a rare chromosome disorder—she had one extra chromosome in her 18th chromosome pair (she had three instead of two). This disorder is called “Edward

Syndrome” or Trisomy 18. The gynaecologist advised us that this is fatal—our baby was not likely to survive long. She might be stillborn, or survive a few days, a few weeks, or a few months, but most likely less than two years after birth. She would have problems drinking milk (from sucking difficulties) and might have problems breathing because of the hole in her heart. She was also expected to be mentally retarded. In any case, our gynaecologist advised that we abort her, but graciously left the choice to us. We knew of her abnormality on a Wednesday, and by the following Monday we had to make a choice on whether to abort her (as I was nearing the last date at which we could legally have an abortion). We were quite shattered and unprepared for this. We called our baby Grace after we knew of her condition.

My husband and I were thrown into great turmoil and confusion. We simply didn’t know what to do. That night, a couple from our church visited us, and they encouraged us to see beyond the present. If we were to keep Grace, she would be grateful to us even if she did not survive. Of course we would have to be prepared to be drained in all aspects (emotionally, financially, etc) if we were to keep her, and to be in and out of hospital all the time. And we had to realise that, whatever decision we were to make, we never blamed each other, but stuck through everything together. We were grateful for this couple’s care and advice.

Many friends helped us by talking and praying, and we also felt pressure from some of the elders in our family to abort the baby and to start anew. But by Saturday, I knew that I wanted to keep my baby—I did not think that I had the right to take her life into my own hands. I felt that this baby was a gift from God, and that only God, as the author of life, had the right to take away her life. My husband differed in his opinion, as he felt that this medical condition did not allow any hope—he worried that he would not be able to cope with Grace’s demands after she was born.

I did not argue with my husband, but felt that I should leave it to God—if He wanted us to keep baby Grace, He had to change my husband’s mind. We prayed at MacRitchie Reservoir that afternoon and spoke to our former pastor at church the following morning. A passage from the Bible (Lamentations 3:31–33) changed my husband’s mind:

“For men are not cast off by the Lord forever. Though He brings grief, he will show compassion, so great is His unfailing love. For He does not willingly bring affliction or grief to the children of men.”

The days of pregnancy that followed were not easy. I often doubted whether we had made the right decision, and whether we knew exactly what we were in for. The thought of caring for Grace after she was born was very scary. What if she couldn’t drink milk? What if in the middle of the night she turned blue? What if...? Once into the third trimester of my pregnancy, when Grace was getting heavier and I was suffering from backaches, I started to complain, “Why did I keep Grace to add suffering to myself? After all she is not going to survive for long...”. But my faith in God sustained me, and I felt that God would not give me anything that I couldn’t cope with, that He had His reasons for giving me Grace, and that Grace was His best gift to me.

We still held onto hope—we met with parents of a baby whose term was marred with an abnormality but who was miraculously born normal. So we sought prayers from church pastors who had miraculously healed others, hoping that God would perform a miracle in Grace's life.

The final weeks were very difficult—at 40 weeks there was still no sign of labour, so at 42 weeks I had to be induced in hospital. Grace was delivered naturally. But she was stillborn. The midwife handed her to me in my delivery bed. It was so gratifying to hold her in my arms, after our long wait. She was so pretty, and looked completely “normal”.

When she was taken away, and I returned to the ward, the truth dawned on me. My baby was gone. The loss overwhelmed me. I had cared and “suffered” for her for 9½ months—why didn't she say “thank you”, why didn't she respond at all? I was angry and sad, and felt as though injustice had been done to me. I cried and cried. My parents and friends came to console me. It was so difficult to be in the hospital seeing other people with happy faces welcoming their newborn babies—while we had to face death in the delivery wards, where one assumes new life begins. The midwives seemed surprised by our decision but they were professional enough to empathise with our situation.

We arranged for her cremation two days later. At the crematorium, the hall was fully packed with church friends, colleagues and relatives who came to support us. We are grateful to them for their support in our time of need. A service was held and our close friend wrote a letter on behalf of Grace to us, thanking us for keeping her. The letter was so comforting to us, for we could at least hear words of gratitude “from Grace” and be able to hear “her voice”. It was a memorable day in our lives.

We have placed Grace's ashes in a Christian memorial, next to a church. Today, we proudly show Grace's photograph to our three other children and introduce their eldest sister to them. On the anniversary of her birth and death we have brought the younger children to pay their respects to her. None of this would have been possible if we had aborted her. Keeping her is the best decision that we have made in our lives.

Grace is always close to my heart. No other children could replace her. Oh how I miss her! I long to hold and hug her again. But I am comforted that I'll be able to do so when I see her in heaven again. In heaven we will meet.

This is the letter written from Grace to her parents by a close friend:

Dearest Mummy and Daddy,

It was not too long ago when you were so happy to learn that I was coming into the world. You gave me such a lovely name too and made many exciting plans for my arrival.

When I was about 20 weeks old, kicking inside Mummy's tummy, both of you heard the shocking news that I had serious problems. The doctors quickly confirmed the diagnosis and advised you to terminate my life. You wouldn't have known it but I waited with bated breath for my life hung in balance. I kept wondering what both of you would do.

Mummy, Daddy, it must have been a most difficult decision for both of you to make. I'm sure there were many nights and days of agony for you two.

Mummy, I can't thank you enough for not taking my life into your own hands. Daddy, thank you too, for standing firmly by Mummy. You both chose to allow God's will to prevail and continued to nurture me inside you. Over the months, I've enjoyed every moment that you've cared for me, loved and cherished me even though I couldn't be the perfect baby that every Mummy and Daddy should have. I've enjoyed listening to your voices as you sang and talked to me.

I'm very sad that I cannot be the beautiful, bouncy baby that you both dreamed of but I would like to know that I have been a much loved and privileged baby. God in His sovereign will has chosen to take me to heaven.

Mummy and Daddy, in the short nine and a half months of my life, you have made it possible for me to have a full life. Thank you. Till we meet again...

Your loving daughter, Grace



Chook Kwan

Ng Chok Kwan

8 November 1965 – 4 July 1994

Madam Lai, now a spritely 72-year-old, lost her 27-year-old daughter over 10 years ago to a long-term illness. Brought up in a traditional fashion, she has had to endure bereavement in the traditional Asian way—silently and alone. She also had to cope with malicious gossip about her contribution to her late daughter's illness and death.

Written by Isabelle Lim, from an interview with Madam Lai, Chook Kwan's mother

Chook Kwan was at the cusp of life. Bright and beautiful at eighteen, she was ready to take on the world. But with one fell blow, Systemic Lupus Erythematosus (SLE) (commonly known as “lupus”) struck my daughter. A big name for a chronic condition in which the immune system becomes hyperactive and attacks normal tissue.

Yet Chook Kwan fought on, acing her ‘A’ Levels with ease and breezing through university. Her determination to excel challenged my two sons to match her grades at university. They couldn’t bear to see their sister, legs swollen from water retention, struggle to catch the public bus to the university campus everyday. So they took turns to ferry her to and from home whenever they could schedule it in their timetables. That was a comfort to me.

After she was diagnosed, I had to watch her grapple every day with hair loss, bloatedness and loss of appetite—all side effects of the medication needed to fight lupus. Yet she refused to let the debilitating illness prevent her from going to work and winning a scholarship to Indiana University for her Master’s degree. My husband was seriously against her leaving for studies as she was already rather ill. But she was determined to go

and excel in spite of her illness. Knowing that it was her dearest wish to pursue an academic career, and that this might well be her last wish and objective in her life, I persuaded her father to let her go. She left with all the giddy excitement of a child who had just taken her first step successfully. For my daughter, it was her first step to fulfilling her dreams—and her last step.

As Chook Kwan beavered away at her studies, lupus cells ate away at her muscles and her joints, little by little. But my plucky little girl refused to let this interfere with her studies. She graduated at the top of her class and wanted to continue with her PhD. Her mind and spirit were willing but her body was failing her. All through her years at Indiana, when we talked on the phone she had never betrayed how much the illness had taken out of her. But my sons, who were also in the States for their tertiary studies, visited her during vacations and always fed back news of her wellbeing to me. The most recent report of their visit was not good. I flew over to bring her home despite her protestations.

When I first saw her, my heart bled. She was swollen and bloated from the medication. Yet Chook Kwan was adamant that she was fine. The next six months were an endless blur of hospital visits, check-ups and searches for a miracle cure. A firm believer and practitioner of Traditional Chinese Medicine, her father took her to reputable TCM physicians, only to come home buoyed for a few days before succumbing to a weary resignation of hopelessness.

In and out of the hospitals we would go, check-up after check-up—I knew deep down that she would never get well. We sent Chook Kwan to the hospital one night after she had thrown up her dinner's contents and experienced breathing difficulties—for the last time. Whisked away for emergency treatment, I never saw her alive again as the doctors couldn't resuscitate her.

When I saw Chook Kwan's lifeless, bloated and diseased body again, I could only rant and rave inside. I was 60. I had already lived my life, I had imagined lying on my deathbed, surrounded by my children who would send me off on my last journey. It was surreal, a white-haired old lady sending a once vibrant black-haired youngster off to the nether world. It was wrong.

I depended heavily on my Buddhist faith to pull me through the funeral where relatives would whisper behind my back about how my daughter's death was my fault. In his grief, my husband blamed me for her illness and my sons turned to denial of the grieving process. After the funeral, there were many long dark days and insomniac nights in our home.

Whether children die in utero, at birth, in childhood, in their teens or at adulthood—whatever the circumstances of their passing—what really matters is our memory of them, no matter how brief or long they were with us. I exemplify this for I felt her in my stomach, heard her first cries, saw her first tooth, delighted at her first step and beamed at her first academic achievement—only to lose her on the brink of her adulthood.

Slightly more than a decade has passed since Chook Kwan's death. I've since gained a daughter-in-law and three granddaughters. I see a flash of Chook Kwan's smile, a twinkle

of her eyes and her dimpled chin on my trio. They are my source of comfort for (unlike my sons) they have unfailingly trooped to the temple where Chook Kwan's tablet is housed, on festival days and important dates of the lunar month. With bouquets of flowers and fruit offerings held clumsily in cherubic hands under their mother's supervision, they openly acknowledge the existence of their late aunt and sister-in-law who I will always wish they had known.

Now That You are Gone

It's not just that I miss her
It's more that I would die for her
But I can't because she's gone.

On good days, it feels like she's ever-present
But on bad days her absence overrules,
God, life's hard now she's gone.

And sometimes I feel, myself, like a child in my grief.
The tears, the frustration,
The not-understanding-the-situation,
Nothing makes sense because she's gone.

If only I could hold her, if I could have her -
Just for a moment to tell her again
That I love her, but she's gone.

Our sublime happiness has died forever
And yet her life was so well lived,
I don't know what that means now that she's gone.

Friends tell me to remember how she was
And yet their children still are,
That's not easy to take now that she's gone.

My darling Daisy, my beautiful girl,
What is to become of your Mummy
Now that you are gone?

– Josie Klafkowska



Daniel

Daniel George Stanley Karagiannis
20 May – 11 June 2003

Jim and Stefanie are Canadian expatriates who have lived in Singapore for nearly three years. (Stefanie was born here in Singapore, and lived here until she went to study in Canada when she was 19—returning every year for holidays as her parents have always lived and worked here). Daniel was their first child and they moved back to Singapore very soon after he was conceived, looking forward to starting their new family life here. He was a beautiful, healthy, strong baby, and the first three weeks of his life were joyous for the whole family. But Daniel suddenly lost consciousness in Stefanie's arms after a normal feed, and he died in hospital after one night on ventilation support. In their anguish, Stefanie and Jim felt bitterly let down by the lack of compassion and support provided by the hospital and mortuary, and were desperate to find a support group here.

Written by Stefanie Zagrodnik, Daniel's mother

On 20th May 2003 at 7:51 am, my beautiful baby boy Daniel was born. I truly felt as though life had really begun for me. I felt alive in a way that I never knew was possible. I was now a Mommy, and I felt the most beautiful, wonderful and loving feeling inside. I was Daniel's Mommy. It was the best feeling in the world.

On 11th June 2003 at 8:11 am, my most beautiful baby Daniel died in my arms. I felt my world had ended, and indeed, inside, a huge part of me has gone. I thought I could write something to tell my story, but in reality it has proved too painful to do. I still want you to know of Daniel and to realise the huge and immediate need for help and support

to be provided to parents who have lost a baby or a child here in Singapore. I have instead included excerpts of a letter that I wrote to a friend some time after Daniel died.

On 10th June in the early evening I fed Daniel. He was feeding as usual. I then burped him and he made a little burp as he sometimes but not always did after the breast. Then I gave him a bottle. All of a sudden I saw him stop making swallowing motions and his face went a bright red / purple colour. I pulled the bottle out and sort of shook him. My Mom was with me at the time and she started to scream, "Daniel, Daniel!" She then grabbed him from me and I could see his mouth was gaping open but no sound was coming out. I was so terrified.

An ambulance took Daniel to hospital. Already he didn't have a pulse and he was so white and so cold. The doctors were able to get a heartbeat again but were never able to get him to breathe on his own again. With a ventilation tube in his tiny airway he was taken to pediatric ICU and while on the ventilator we held him as he died at 8:11 the next morning, on 11th June 2003. All night long I stroked his soft little head and told him how much his Daddy and I loved him. We held him so tightly and sang little songs to him and told him again and again that Mommy and Daddy could only love someone so beautiful and so good as himself. His little body felt so so cold and he was not the Daniel we knew—Daniel was always so pink and warm and mobile. I can still feel his soft little head and see his big beautiful eyes as he looked at his Mommy when I fed him.

We held a funeral for our little Pumpkin here and then took baby Daniel back to Canada to bury him with my Grandma and Grandpa. I loved my Grandma and Grandpa so much and Daniel is now sharing a grave with my Grandma. It is the worst thing to have to bury your own child, to know that they have gone and that you will be without them until the day you yourself die.

I cannot stop crying, the pain is just too much. Jim and I are devastated. It is impossible to believe that my beautiful little boy will never come back. Jim and I feel like we have died inside. We really wish we had died too as life without our little one is impossible. We stare at his little empty bed and smell his little duckie blanket and we cannot, just cannot accept that he is no longer here. I love my little Daniel so very much and I just want to hold him again and to touch his soft little head and kiss his chubby cheeks and it kills me to know that I will never be able to do anything with him again. All I can do is lie in my bed and cry for my baby who will never grow up to be a big boy and who I will never be able to play with or sing songs to or do anything. I just wanted to be Daniel's Mommy.

When he died, no one approached us about providing support or offering counseling, no one came to comfort us, no one gave me anything for my milk supply, instead, we were hurried out of the hospital and told, "Could you settle your bill please, we're changing shift and we'd like you to do that before you go." My most beautiful love had just died in my arms and all I could do was lie on the cold hospital floor and scream and scream and you want me to pay my bill? Could we see Daniel again? No, that would not be possible. Could we have a lock of his hair? Why would you want to do that? No comfort was

given, no privacy was made for us. In a large PICU room my beautiful son lay dead on a bed so many times too big for his beautiful tiny body and his Mommy and Daddy were being “hurried” along to pay the bill.

We had to go to the morgue to identify our beautiful Daniel. I still cannot believe that Jim and I have had to identify our son as he lay cold and dead on a stupid cold tray all wrapped up in a huge blue sheet. We were given a number and told to wait our turn. When they called our number we got herded into this barren, cement floored room to see Daniel for one last time behind a glass panel. They asked us if he was our son, and then I just broke down and lay on the ground wailing aloud and sick to my stomach. Could we leave now please, others are coming in. Hurry up. You’ll never see your son again...but hurry along. Oh God, I hate the people who work there. Can we not just have a few moments more please to look at our beautiful, beautiful little boy, please, for one last time? No.

The autopsy done on Daniel said he died of pneumonia. His Neonatologist, other doctors consulted and we ourselves find such a claim incredulous. Given his lack of symptoms and the suddenness of his death, other doctors have told us they believe his death was due to a cardiac dysrhythmia—a problem affecting the conduction of energy across the heart muscle. We have researched this extensively, consulted doctors in Canada and the United States and are having his cord blood genetically screened. Our search for a medical reason for Daniel’s death is done alone. Once a baby has died it seems the outside world cares little to assist in investigating why. It is vital for us to do all we can to understand why Daniel died. We realise the ultimate answer may never be known, but as Daniel’s parents we feel we must try our best to uncover whatever we can about the reason for his death.

The lack of support and compassion given to us has only exacerbated our agony at this terrible time. At a time when we needed time, patience, gentleness, kindness and privacy, none have been forthcoming. The pathologist who carried out Daniel’s autopsy was the one exception in our horrific experience. We are so grateful for his empathy and concern. The compassion he showed us was so vital and yet so rare.

A year and a half later, I am thankful to say that after an immense and desperate search, we did find a sympathetic counsellor who helped us talk about our son’s death and our immense feelings of despair. I have also found great comfort in meeting other bereaved parents through the setting up of CBS. Their support has been invaluable in helping Jim and I to carry our pain as we try to go on with our lives. I passionately hope that CBS will be able to make a difference—particularly in the training of professionals in promoting best practice in bereavement support—so that others do not have to experience the painful lack of compassion that only increased our agony at the time of Daniel’s death.

Our pain is still incredibly intense and perhaps it always will be. You do learn how to put on a smile in front of others, but when you lie awake crying at four in the morning, crying for a child you will never see again and reliving every painful memory, only you can realise how suffocating your pain can be. People ask me, eighteen months after Daniel's death, if I often think of him—how can they begin to understand? How can you explain that an hour does not go by when I don't think of baby Daniel, wonder what my little boy would have been like, and so desperately long to hold him again.

Dearest Daniel

Daniel, the nine months you were in my tummy were so wonderful. The three weeks you were physically here with us were the most beautiful we have ever had, and ever shall have.

We watched in amazement as you so intently and eagerly turned your little head to listen to your music box play “Teddy Bears’ picnic”. We laughed lovingly with you as you scowled so sweetly when we gave you your first bath at home. We walked outside in the garden with you, Mommy telling you all the names of all the plants growing in our tiny yard. Mommy was sure you understood every word of what she was saying! We so proudly showed you off when we took you out to tea with your Grandma, that was such a big day for you! We loved showing you your first rain shower and promised you that we would all play together in the puddles when you were a big boy. We couldn't believe how quickly you could wriggle out of your blanket when we thought we had snuggled you as snug as a bug. We felt we couldn't hug you tight enough or often enough; you were so beautiful; naïvely we thought we would have a lifetime to hug you.

Daniel, you ARE our son and always shall be. You will always be our beautiful baby. Mommy and Daddy will always love you. Always.



Edward

Edward Burridge
18 October 2002

Susan and Rick are New Zealand/English expatriates who have lived in Singapore for eight years. They were delighted to conceive their third child, Edward, and the whole family was looking forward to his arrival. But at 30 weeks of pregnancy little Edward's heart suddenly stopped beating for no apparent reason. His parents have had to learn to cope with this illogical and terrible loss, and regret the lack of hospital support and understanding in their moment of grief.

Written by Susan Burridge, Edward's mother

On 17th October 2002, I arrived at the hospital for my antenatal appointment, which I had arranged four weeks previously when I was last there. As usual, the nurse took my blood pressure and weight gain, which were both fine and had been throughout this pregnancy.

The Doctor ushered me into his consulting room. I was familiar with him, as he had delivered my two other children (Lucy and Holly). It was always exciting to see him and we had a brief chat. After acknowledging that I had had a good weight gain, he felt my tummy and said the baby was in the breech position. Not a problem as I was 30 weeks and there was plenty of time for the baby to move.

He then did a routine scan. That was where everything started to go wrong. He asked me in a worried tone when the baby had last moved. I was beginning to feel threads

of coldness creep over me. I knew that the baby had moved the night before and remembered watching my tummy move while I was lying in bed. I had been amused at all the activity inside me. I hadn't felt movement that morning but wasn't monitoring it nor at all concerned as it was still only 9.30 am and I had been busy running around trying to get to my appointment on time. The Doctor then held my hand and told me he couldn't find a heartbeat and that he thought our baby had died.

My mouth turned dry and all I could think of was NO, no, no. I kept asking if he was sure and he said how sorry he was. Then I just kept repeating, "OK, OK" in this unusual voice, trying to comprehend what was happening. My body felt completely numb as though somebody had hit me really hard. Somehow I managed to telephone my husband at work. He was devastated and came to the hospital immediately. I was put in another consulting room to wait for him to arrive. The nurse stayed with me and we waited. The feeling was pure disbelief, shock and unbearable sadness. When Rick arrived, we fell apart and cried.

We were sent down to the radiologist so they could confirm there was no heartbeat on a more detailed scanner. It was desperate seeing all the people waiting for their 20-week scans with big smiles on their expectant faces. We had tear-stained faces and were in total shock.

Only a few weeks earlier, we had been there like them. Everything felt surreal like it was a dreadful nightmare. We kept hoping there had been a terrible mistake and the radiologist would find a heartbeat. The radiologist confirmed our nightmare that in fact our baby had died. We then were sent back up to our doctor's room. There, he told us that I needed to deliver the baby. Either by allowing it to come naturally, which could take up to four weeks or by inducement—which he recommended. We chose the latter option. It somehow felt wrong having our baby inside me if it wasn't alive. At that point I asked what sex our baby was. We were keeping it as a surprise, but I suddenly needed to know. The doctor told us it was a boy. At that point, we both broke down as reality kicked in. He would be the son we had dreamed about.

I was admitted to hospital that afternoon and given vaginal pessaries to induce labour. By 7.00 am the next morning nothing much was happening and we were getting desperate for this part of the nightmare to be over. They gave me an epidural and oxytocin, which brought on the labour quickly.

Our son Edward was born on 18th October 2002. He was beautifully perfect and it was so desperately sad that we couldn't have him alive. I remember thinking how quiet the delivery room was. No baby crying—just this dreadful silence. We both held him, kissed him, said a prayer and our goodbyes. He will always be our third child and our beautiful son, Edward.

No photos were taken of our little boy. I really feel the hospital failed us in respect of support immediately after his birth and helping us provide memories, which we could keep. I would never want anyone to feel that their baby somehow wasn't important

enough. It is obviously such a distressing and confusing time for parents and they need to be guided by the hospital staff. Taking photos, a lock of hair and footprints should be mandatory. A birth and death certificate, no matter what the baby's gestation. Suggestions and guidance for a burial or cremation would have been helpful. We had to ask for these, unsure if it was even okay to do so. We were made to feel like Edward was somehow not a "real" person and so "did it matter?" I feel so cross about that now.

We were also made to feel like there was no time and everything had to be done quickly. He was whisked away once we had said our initial goodbye, so soon. What if we had wanted to see him again? He was actually cremated that day! It was all very unnecessary and this definitely made it more difficult and traumatic for us. Fortunately, a very great friend raced down to the crematorium (just in time) to take his footprints. They are all we have of our beautiful little boy. I am so incredibly grateful to her for doing that for our family and us. I look at them every day and really don't know what I would do if I did not have them.

Seven long weeks after Edward's birth and death we went away on a family holiday. It was wonderful to escape for a while, although I am very glad that we spent some time facing reality and dealing with people before we went. It was reassuring to know while we were away we had already "faced the world", so this wasn't looming over us when we returned.

The holiday enabled us to have some special time together and also gave Rick a chance to talk to me about how he felt. Men are hopeless at talking to each other about these things. I think it really helped him, although he has never found it as easy to talk about Edward as I do, so the grieving process is different.

Life went on—but sometimes when I was doing something very ordinary, like driving to the shops, it would suddenly hit me like a ton of bricks. I would feel all dry in the mouth with the wind completely knocked out of me. I found it difficult to believe any of this had really happened to our family.

Gradually we began to feel that life was getting back to "normal". When we lost Edward I thought I would never smile again, and then two months on we realised that we were smiling, going out with friends, socialising and trying to heal. I came to realise that doing these things wasn't belittling Edward or what happened in any way; it is just what had to be done for us to heal. Time helped us and I am sure it will continue to do so but I don't think we will ever actually get over Edward's death—you just learn to live with losing a baby.

We talked about trying to have another baby too. This is something we desperately wanted and I found it frustrating and difficult having to wait the suggested three months by the doctors until we could start trying again. It seemed that everywhere I looked, there were pregnant women or newborn babies around me.

When I did fall pregnant we were both delighted, and felt exceptionally lucky to have been given another chance somehow. But I felt very upset when people suggested

farewell, my child

that this baby would replace Edward—I can never replace him, nor would I want to. He was and is our third child and we will always love and miss him terribly. The new baby growing inside me gave us hope. Although I was completely terrified that we would lose this baby too, I felt fortunate to have been given another chance.

I found the pregnancy VERY stressful. Everyone seems to feel that “lightning never strikes twice”—but by being pregnant again, I risked being struck again. I had to change my obstetrician too, as I couldn’t bear to keep going into that same room which I was in for all of Edward’s check-ups. It was too hard to be reminded during every visit of that awful day when I found out he had died. I also needed a doctor to completely understand that although everything might look fine medically, I wasn’t fine. I needed all the support and encouragement I could get. I found that doctor and he made me think we might just get through this with a live little baby at the end. I will always be grateful to him for his professionalism. No matter how silly my questions or feelings were, he took them very seriously and I felt I was in good hands.

On 15th October 2003, our second son and fourth child, Thomas, was born alive and very well. We were delighted, relieved and exhausted!

Three days later was the first anniversary of Edward’s birth and death. Complicated emotions swung from joy and elation at Tom’s birth to incredible sadness and despair at Edward’s death. We managed to leave Tom, Lucy and Holly with somebody for an hour on Edward’s anniversary while Rick and I spent time alone thinking and talking of him. I was pleased we did that. It was a good, important thing for us to do.

I constantly wonder if Tom is anything like his brother Edward. Not so much in looks but in personality. I feel that having another boy has given me an insight into what Edward would have been like. I also feel that Tom will miss out on having a live brother. One he could play with and that saddens me too. For him and Edward.

Rest in peace my little angel boy.





Faith

Faith Yaw Fong Yin
11 September 1996 – 31 January 1998

Faith was the firstborn of Christopher and Jacqueline. After a bout of measles from which she couldn't seem to recover, a check-up showed that she had a large tumour in her brain. First diagnosed as benign, the tumour was actually fiercely malignant. After three operations, it was found that the tumour has metastasised to her spine and her chances of recovery even with chemotherapy and radiotherapy were slim. She passed away peacefully at 16 months on 31 January 1998.

Written by Christopher Yaw, Faith's father

The longest walk of my life was carrying our eldest (and at that time only) child, Faith, from the children's ward where she had passed away about an hour ago to the mortuary at the basement of the hospital. It is said that when you are about to die, your whole life flashes before you. Our daughter had just died and, during that very long walk, her life and her bravery played continuously in my mind.

While we were relieved because it was the end of a nine-month long ordeal that drained our resources—financial, emotional and spiritual—and took us through hell, it was also a very painful and lonely time. Very few friends stayed on with us during this long journey, many because they didn't know what to say to us when they were with us and felt awkward. While some relative were supportive, ultimately, we had to depend on ourselves to keep vigil during Faith's numerous hospital stays, taking turns to be with her, something that only parents would do.

Faith was born normal and healthy, though we had a fright during Jacqueline's pregnancy as doctors detected a cleft in her brain. Little were we to know what the cleft would become nine months later. While her development was slow, we didn't notice it as

we were first-time parents. It was only after a bout of measles when she was seven months old and she didn't seem to recover from it that we thought something could be wrong, though the GP who diagnosed her measles kept telling us that some children do take longer to recover. But we did notice that there was some regression in her development. Certain things that she was able to do when she was younger, like sitting up straight, became difficult. She would topple backwards when left to sit on her own.

So on a June afternoon in 1997, we took Faith to the hospital for a check-up. The doctor ordered a scan and, to our shock, they discovered a huge tumour in her brain. We were sent reeling. Where did it come from? After a long wait into the night, we were told that she had a benign tumour that was affecting her motor functions. How naïve were we to believe that. If it had not been our daughter and I had been of clearer mind, I would have questioned how a “benign” tumour got to be so big in nine months. But we were in shock and our mental faculties were temporarily addled. We believed the surgeon who told us that hers was a rare form of benign tumour.

After an operation to reduce the size of the tumour, Faith seemed to recover well from it. But that was not to last. Her symptoms came back within a month. This time, the same surgeon who operated on her told us that she had hydrocephalus, a blockage in her brain where fluids could not drain. So another operation was scheduled that left her with a tube running from her brain to her stomach; a tube that would supposedly drain the fluids from her brain to her stomach; a tube that was to be there for life. It was difficult but we accepted that if that was how she had to live, so be it.

But that was just the beginning of what was to become a nine-month journey into hell. The results of another check-up a few weeks later shocked her surgeon as much as it did us. The supposedly benign tumour had re-grown back to its original size. In panic, the surgeon told us that we should consider sending Faith to the UK for treatment. It seemed that he had given up.

It was then that we moved Faith to another hospital at the suggestion of a relative who was a doctor. At the other hospital, Faith had her third operation. Again, part of the tumour was removed as the new surgeon was operating under the impression that the tumour was benign. It was only a week later that the final shock came. After testing the tissues removed, the surgeon confirmed that Faith had a malignant tumour in her brain, one of the more common types. How the professionals at the previous hospital missed this common tumour (called medulloblastoma) was a mystery. The options to try to cure her were straightforward—chemotherapy and/or radiotherapy.

But time was running out. Another check-up later confirmed that the malignant cells had already metastasised (medical term for spread) to other parts of her body, particularly her spine. The doctors gave Faith no more than a 10%-chance of survival with treatment. It was now six months since she was first found with a “benign” tumour in her brain. We were drained, financially and emotionally. Jacqueline and I had also used up all kinds of leave that our respective organisations had to offer, official and unofficial. We didn't think we could go on any longer, hoping against hope. And do we want to put Faith, who had braved through three operations, through chemotherapy and radiotherapy for a 10% chance of survival?

As Christians, we believe in miracles. But we also believe that the Lord giveth and He taketh away. The choice was taken from our hands when Faith had breathing problems during a stretch when she was at home shortly after Christmas 1997. By then, she was bedridden and incapable of swallowing. We had to feed her using a tube through her nose. And often, she would throw up her feed. She also couldn't lift up her neck any more. It pained us greatly to see her in that way, even after the surgeon told us that she was not feeling much pain because the tumour was pressing on her nerves. Little comfort.

We rushed her to the hospital. She recovered after a week but had to remain in hospital as she caught something infectious. That also precluded any operation. There was no Quiet Room then but the kindly surgeon who operated on her ordered her to be put in isolation because of her infection. We couldn't afford a single room any more and had to put her in a four-bedder when we checked her in. And that would eventually be the room where she would die. In a way, God had made the decision for us and even provided a room for us to be alone with her.

On the Saturday that was to be her last, Jacqueline had just gone home after staying the night with Faith. Her blood pressure and oxygen level dropped suddenly that morning. Doctors rushed in, pumped oxygen in and got her pressure back to less dangerous levels. They told me to expect anything. I called Jacqueline to come back to the hospital. Strangely, on that day, three pastors came to visit her. They had been coming to visit her in the hospital and at home irregularly. Jacqueline came back in the afternoon and Faith seemed to be back to her responsive self. After a visit by her friend, Faith soiled her pampers. As we cleaned and changed her, we noticed that her muscles had relaxed. We didn't know it at that time but she was about to leave us. We called her but she didn't respond. It was then that we realised that that could be it. I grabbed a stethoscope that was hanging on her cot and tried to listen for a heartbeat. I found one—the last one.

After nine months of suffering, God had decided to take Faith to a better place. We hugged her and stayed with her for some time before I went out to call for the nurses. Faith was cremated two days later at a small gathering of the relatives and friends who hung in there with us. We didn't call many people because we thought it would be meaningless to call people whom we had not seen in months just to come for a funeral.

Through the maze of questions of whys and wherefores, we have come to accept that God's way is higher than our way. And this is the road He has set for us. When we took Faith's ashes to a small chapel for internment, an old elder there told us not to be sad; God would bless us with many more children. Cold comfort, I thought. We were feeling definitely morbid. So morbid that I guess God decided to wake us up. During a drive to the chapel a week after Faith had left us, we were talking in the car about maybe God should have taken us all home. Why leave us here? Suddenly, I lost control of the car. It spun once and ended on the kerb, facing the oncoming traffic. Miraculously, none of the cars behind us hit our car. It was at that point that we suddenly realized that the living must go on living. Our time was not here yet.

And the cold comforting words of the old elder is becoming a reality—we now have three children, a girl whom we named Lois Faith in memory of Faith, and two boys, Luke and John. Though Faith has left us, faith will never die.



Grace

Grace Watkins
30 April 2003

Trish and David are Australian expatriates who lived in Singapore for three years (they have just returned to Australia). They had tried for many years to start their family and were overjoyed to conceive Grace. Trish struggled through the early months with terrible morning sickness, but as her due date approached their excitement mounted. Worried about the SARS epidemic sweeping the region, they decided to travel to Australia for Grace's delivery. But their dreams were shattered when their longed-for daughter suddenly died at 38 weeks of pregnancy. David refers to their experiences as a "long, hard journey".

Written by David Watkins, Grace's father

In the months shortly after 30th April 2003, many people asked me the simple questions, "How's Trish? How are you coping?" Simple questions—but questions for which there was no answer. No words could describe our experience. And later, the only way I could respond was to say that it is a long, hard journey.

And sadly, it is a journey without end. In the year in which we die, we will have both celebrated and mourned Grace's birthday. It may be her 3rd birthday or her 43rd birthday but we will always remember Grace.

We will remember her mother's bulging tummy, how vigorous and active Grace was, we will remember our excitement and our anticipation.

And we will remember the shock, the disbelief and the numbness.

And we will remember her beauty, her smell and her warmth. We will remember the peace and calm she brought us when she entered the world.

We will remember the sadness, the loss, the emptiness—and worse, we will constantly live these emotions.

On 29th April 2003, Trish and I looked at a lifeless screen—the ultrasound image that should have shown our active, healthy Grace—but she was quiet, still and dead.

At that moment, I felt as if I had tumbled into a black hole and all around was darkness. Like Alice in Wonderland falling down the rabbit hole. So much is unknown—when will we stop falling? Where will we land? Will we find a way back?

I remember thinking—What will happen to Trish? Being a mother to our little baby was her sole goal in life at that time. And in that moment, so began our long, hard journey.

Over many years, we have learnt patience. Making a baby is not as easy as we expected. In the period after Grace was conceived, we lived through a traumatic and stressful period. Trish's sister Gemma was in a terrible car accident and, despite expectations to the contrary, she lived and recovered. And at the same time, Grace lived and grew.

By Christmas of 2002, we started to believe that we would this time become parents, that we would have our own little baby. Trish was now about 20 weeks pregnant, the unpleasant morning sickness had stopped, a New Year was ahead of us—this was the year in which our baby would be born.

We wrote a diary for our little one—to record our excitement and our hopes. I wanted our little one to grow up knowing that anything was possible—that there were no limits to what she could do.

Due to SARS, we returned to our home of Sydney to deliver our baby. We left Singapore when Trish was about 35 weeks and remained in self-quarantine for a week. We had a 37-week check up with our Sydney doctor—everything was fine. Then our world changed forever when we went in for a normal 38 week check up on 29th April 2003. There was no heartbeat. How could this happen? Surely at this stage, babies don't just die?

That evening, we met Deb. She is a counsellor who specialises in working with people who have lost little ones. She explained what our baby might look like—how the skin may have blistered depending upon how long ago she had died. We felt sure that our bub had been alive just 24 hours ago as Trish had felt movements the previous night.

The next day, Trish was induced. We arrived at the hospital early in the morning and Trish delivered our beautiful baby girl at around nine that evening.

I had anticipated that the moment of birth would be the culmination of the terrible process, a horrific moment—but it was not. Grace was perfect in every way. Beautiful face, wonderfully warm, chubby legs, her eyes shut—she looked like a perfectly contented, sleeping child. We were filled with a calming sense of peace and love. Even in death, Grace could bring us love.

Our parents joined us soon after and Deb unobtrusively orchestrated a normal newborn routine. We bathed and cleaned Grace, we dressed and we held her. We took lots of photos, we took her handprints and footprints and we cut a lock of hair. Grace will be with us always. We smiled—we did not cry. Grace was blessed by a priest. It was a lovely time. We had so little opportunity to be a family together with Grace and this was a wonderful family time.

Exhausted, bewildered, uncertain—we fell asleep that night with Grace in a cot next to our bed. Mum, Dad and our baby.

The next morning, I kissed Grace. I was shocked that she was ice cold. But I discovered that when I held her hand in mine, her body would warm up. We could give her warmth.

Some of our siblings came that morning to meet their niece. There was much sadness and many tears—mainly from our siblings. We had already lived with the reality of her death for a day (it seemed so much longer) and we had enjoyed the lovely evening last night with Grace. At that stage, we became the strong ones to help our siblings deal with the loss.

Later that day together with Deb, we began to organise where we would bury Grace. We began planning her funeral Mass. We were in a state of shock that this was the reality that we were dealing with—but there was now so little that we could do for our beautiful girl, and we knew that a loving farewell was a gift that we could give. So we put our emotions and energy into that.

The next day, Trish's sister Gemma came to the hospital to meet Grace. I can still see Gemma entering the room in tears—but by the time she had walked to the cot, Gemma was smiling, looking lovingly at her niece and then cuddling her. Even in death, Grace could bring pleasure.

The evening before the Mass, we visited Grace again, together with Deb. We held her, we washed her, we dressed her, we wrote her a letter, we filled her little coffin with roses, gum leaves and a toy. The time had come to say farewell and we placed her lovingly in her little box. We sealed the lid. How could this be happening?

Grace's Mass was on 5th May 2003. Trish and I delivered a eulogy. The depth of our pain was a reflection of the strength of our love for Grace. I recall sitting in the church towards the end of Mass, not wanting to leave. It was warm inside and raining outside, there was beautiful music and we were with family and friends. The same people we had intended to invite to her christening. But our reality was that we had to leave for a cemetery.

We carried our little one out of the Church and together with the priest, the three of us went to the cemetery and placed our little one in the ground.

The pathology report on the placenta indicated that there was some clotting. A very uncommon occurrence that could not be explained and that would not be expected to recur.

We have cried, we have despaired, we have asked why, we have laid awake, we have wondered if life is worth living, we have seen doctors, we have sought help, we have felt the presence of Grace—we have struggled to endure. It is a journey that no words can describe and that no one who has not trodden that path can begin to understand.

As a husband and a father, there are two terrible pains. The loss of a child—experienced as a man. Then there is the pain of seeing my wife experience the loss of a child—experienced as a woman. There is a depth to the pain that Trish feels that even I cannot understand. I look on and see my wife broken, pained, destroyed—and there is nothing I can do. I am powerless.

My creed—that I must have recited thousands of times—is that “We will be OK.” It is not very poetic, but it is unshakeable.

In all of the terrible sadness and loss, I have found some slight comfort. I have thought that as I lie on my deathbed, I will be excited by the prospect of meeting our child. Of seeing our beautiful Grace. We have suffered a huge loss to be deprived of her life and of her being part of our lives, but in the time of death, she will await us. And at last, we will be able to find some peace and happiness together with our little girl.

Another time, I imagined dancing with Grace as a little girl, maybe seven years old. Happy, carefree, smiling, laughing. And I thought that many parents and fathers would look back on such days and wonder where did all of that happiness go. Life changes as parents age, as children grow up. And for some, life changes in a way that hardens and harms relationships. But for us, we will not experience the loss of love or the lack of care. She is forever our beautiful Grace. She does not change. She remains beautiful. Whilst we have not had the joy of dancing with a seven-year-old Grace, what we have in our hearts and memories can never be tarnished by subsequent events. She is and always will be the perfect daughter.

I remained forever hopeful. I could not accept that our life would not come to a better place. I remember the day after the Rugby World Cup final, 23rd November 2003—this was to have been the weekend of our child's Christening in Sydney. We had planned how we would travel from Singapore to Sydney, bringing our six-month-old baby to her country for the first time. I would go the Rugby World Cup games in the last week of the tournament. I had imagined placing our baby on the ground—the land of Australia—as we left the airport terminal. I had imagined taking her to Balmoral Beach and running her fingers through the sand. I felt desperately sad—life seemed to be without joy, something to be endured rather than lived. I felt as if I were holding my breath—waiting—focusing on doing all we could to achieve the only thing in life that we wanted and needed. But no matter how hard it was, I resolutely refused to accept that we would not have another child. I remained convinced that we would have more children and that Grace would always be our first. Our other children would not erase the pain of the loss of Grace—that pain will be with us till our deaths. But our children would bring joy again to our lives. They would provide a counter-weight to the terrible pain and loss.

As I write this in February 2005, Max and Sophia are peacefully asleep in their cots. Happy, loving and wonderful children. We adopted both Max and Sophia from the same orphanage in Cambodia. We are so lucky, they are so lucky. It is a wonderful outcome—all brought about by Grace. If Grace was with us today, we would never had met Max and Sophia. Coincidentally, Max was born on the same day we buried Grace.

And Trish is about four months pregnant. It was a joy beyond words when we found out that we were pregnant. But nine months is such a long time to cope with the anxiety of another pregnancy. Will it all be all right this time?

I am optimistic. I know that a happy and healthy baby will be born in the middle of this year. Our children will be all loved, loved always—all four.

The following poem was part of our eulogy for Grace:

Grace

You were nurtured, loved, welcomed, anticipated
Over nine months, by so many
And in an instant, you are gone
We cannot understand why
How could anyone want you and love you more than we?
We have just one need
That cannot be met
That you were with us now
In too short a time
You gave us love, strength and hope
You were beautiful, perfect, peaceful, graceful
You made us a family
We have
Layers of loss
Forever sadness
Empty hands
And aching hearts
The intensity of our pain
Is only a reflection of the depth of our love.



Jakob

Jakob Ajani Wu Shao
2 October 2003 – 5 July 2004

Jakob was born prematurely at 33 weeks of pregnancy. His parents Walter and Monique loved and supported him through his struggles to deal with endless problems and complications—and after 9 months and 3 days he gave up the battle and died of multiple organ failure. Jakob's father Walter has written a letter from his beloved son to tell his story, and adds his own personal letter to Jakob.

Written by Walter Wu, Jakob's father

Dear Uncles and Aunties

My name is Jakob Ajani Wu Shao, son of Walter and Monique. I was born on 2nd Oct 2003 (six weeks early) and weighed 1.43 kg. When I came, the doctor told my Dad that I would have to stay in hospital for at least one to two months. He also said that I would have some problems and that he would do his best to make me well.

Since my lungs were weak, the doctor used an ETT tube to help me breathe. After three days, he said that I had an open blood vessel near my heart. Most people call this condition a hole in the heart. So I was given medicine to close the hole. He also ran tests on my liver as my jaundice level was very high. I also suffered from fits and even choked on my milk several times. A nurse taking care of me said that I scared her as I did not breathe at all. The doctor also said that my body could not absorb the milk coming into my stomach.

A month later, the oxygen tube had been removed but I still needed to breathe with a box around my head, providing me with extra oxygen as my lungs were still weak. I also had a tube that sent a little milk through my nose to my stomach continuously as I couldn't stomach too much milk at one time. The doctor was also waiting for results from tests on my liver as he suspected I had liver disease. The nurses at the hospital thought that I might need to stay in the ICU for about three months or more.

After just over one month, I was transferred to another hospital. A few weeks later, the doctor told Daddy and Mummy that I had Lissencephaly. Daddy had already suspected this and was not very surprised. Worried about my condition, Mummy and Daddy cried. Then came another shock for them in January 2004 when the doctors discovered that I had Hiatus Hernia.

At this point, I was still breathing with a box around my head. Several times, my brain stopped sending messages to breathe and frightened everyone extremely. I even had a Code Blue announced once by a nurse aunty. Wow!

The next big thing was a double procedure on my stomach. A doctor used keyhole surgery to repair the Hiatus Hernia, perform a Fundoplication, and put a Bard button into the stomach. This meant that my stomach was finally in the correct position and I could also drink milk without vomiting so easily. The button let my parents pour milk through a tube directly into my stomach. I still couldn't swallow without choking. This would aspirate milk into my lungs and would cause pneumonia. The Fundoplication reduced this greatly and I was able to retain my feeds.

In May 2004, the doctors advised Mummy and Daddy that I needed a tracheotomy to help me breathe easily. The surgery was faster and shorter than the previous one. I was then transferred to the Children's Intensive Care Unit (CICU) where I would stay for a week. Then, I was transferred again. This time, to Ward 65, a stepped-down ward, different from the CICU.

I didn't like this place very much. Many visitors did not respect that my neighbours and I needed quiet rest to recover well. I remembered one particularly rude visitor (a mummy) who even sneezed in my direction—how inconsiderate! I also remembered Daddy being very upset about that. I spent a very uncomfortable two weeks in that ward.

In the week leading up to 11th June (my date of discharge) my parents were busy getting everything ready for me. I was very quiet due to some changes in my body. But the doctors thought that I was fine. On 7th June 2004, one of the consultants wanted to increase my feeds over a longer stretch instead of giving me less over a shorter period of time. Daddy didn't think it was a good idea. I started breathing very hard and my tummy was full with milk spilling out of my button. Daddy stopped them from feeding me and wanted the feeds to be reverted to the original volume. That night, he and Mummy stayed back late to make sure that my breathing was ok before they went home.

Unfortunately, the next day, my father received a call from the hospital. I couldn't breathe well and my heart rate was very slow. The staff took a long time to resuscitate me. They took blood to do ABG's and other tests. My potassium was very high and my sodium was very low. The doctors told Daddy that my glands were not functioning well. This was why my heart rate, blood pressure and temperature were all very erratic. They had to give me steroids to help me get better.

Over the next few weeks, I became swollen and nothing the doctors did worked. They ran tests and put me back on a glucose drip because I could not retain my milk. My pores were getting so big due to the swelling that I was leaking fluids through the pores on my back. My lungs were also flooding with fluids. The doctors had to insert a needle (chest tap) to draw out the fluid. They drew out 150 ml of fluid—the same amount as a small mineral water bottle. They wanted to repeat the chest tap the next day but I stopped breathing just before they began the procedure. This time, it was bad. Daddy thought I was gone and he nearly broke down. The doctors revived me and I was sent down to CICU.

Based on the tests and my condition, a new name was taught to Daddy—Nephrotic Syndrome. My kidneys were leaking protein and not washing my blood properly. The only treatment was to give me lots of steroids. Not to build muscles but to help my organs work better. Don't forget, I also had adrenal gland failure.

Daddy and Mummy were told a week later that my condition was not improving and the doctors were now in "palliative" mode. That big word meant to make sure I was comfortable because no medicine was going to save my life. Daddy and Mummy wanted to bring me home and a doctor said he would try to stabilise me.

On 3rd July, Mummy was happy because I tried so hard and I looked much better but I was gasping for breath all of the next day. My breathing only stabilised at night. My heartbeat was erratic and the doctors told Daddy and Mummy to prepare for the worst—yet again.

Then, 5th July came and my heartbeat slowed drastically. Daddy and Mummy were called at 7.40 am and told to come immediately. Thanks to the peak hour traffic, they only reached me about 8.35 am. They held me as my heart stopped and I slipped away.

Dear Jakob,

I want to say that I love you. I know that the nine months you spent in hospital weren't fun. But you were very brave. Every time you smiled, you brought so much joy to us. Your moments of pain were painful to us too. And yet, you fought on. You fought when the doctors gave up hope. You showed us all how strong you were.

Daddy wants you to know that Mummy and I will be strong, so don't worry about us. You're with Jesus now and there is no more pain. Daddy will take care of Mummy so you can go in peace.

Dear dear Jakob. We will really miss you so much. And yet we know that this is all for the best. I love you so much that each time I had to do something I knew might be painful for you, it hurt. Please forgive me.

Love

Daddy

Walt

We Will Remember

They shall not grow old, as we that are left grow old:
Age shall not weary them nor the years condemn.
At the going down of the sun, and in the morning,
We will remember them.

– Laurence Binyon



Jordan

Jordan Tan Wei Kai
9 November 2003 – 19 June 2004

Proud parents of six-month-old Charlotte, Adriana and Martin were surprised but delighted to learn that they were pregnant with twins. But their excitement turned to fear and sorrow when the twin boys were born prematurely at 30 weeks of pregnancy. Justin was fine, but Jordan suffered severe problems and complications and spent most of his little life in hospital. His mother Adriana tells of his valiant struggles.

Written by Adriana Lim, Jordan's mother

Last year in May 2003, I found out that I was pregnant. It came to me as a shock. At that time, our eldest girl Charlotte was only about six months. We were not prepared to have a new member of the family just yet. But before long, we were all delighted to find out that I was pregnant with a pair of twins!! I was happy, yet apprehensive, having no idea how I could cope with three. Nevertheless, with my mum's promise to help me through, I soon found myself anticipating the twins' arrival. I am really lucky to have a great mom!

Things didn't turn out well, however. On 8th Nov 2003, while attending our best friend Andrew's wedding, my waterbag broke before dinner started. My husband Martin rushed me to hospital and doctors tried their very best to stop the labour as the twins were only 30 weeks old, so very premature. After about seven hours, when nothing had worked, finally the doctors performed an emergency C-section. On the morning of 9th November 2003 at 4.00 am, Justin and Jordan were born weighing 1.25 kg and just 975 grams respectively.

Hours later, Martin came to visit me at the hospital ward after seeing our babies, bearing news that Jordan had a serious problem with an imperforated anus. This came to me as a huge blow and I felt devastated. But with the help of my very supportive mother, my two younger brothers and my close friends, I quickly pulled myself together to face the challenges ahead. Little did I know the future ahead was heartbreaking.

As the twins were so premature, they were sent to the Neonatal Intensive Care Unit in the hospital for observation. While Justin was doing fine, the doctors had to perform an operation on Jordan just days after he was born, to open a hole at the side of his abdomen (colostomy) for his motion. He also had a series of other problems including a heart problem leading to difficulties in breathing, septic ileus with abdominal distension, low-lying spine, amongst others.

Two weeks later, doctors performed another emergency operation on Jordan's small intestine which had holes in it, causing it to be stuck. This meant severe indigestion and poor Jordan's tummy was like a balloon. So we spent the next few months going to hospital every day to visit the boys. Justin was growing steadily but Jordan's condition always fluctuated and I've forgotten the number of times I almost collapsed seeing him suffer. Gradually, we learned to not think or worry too far ahead and just live from day to day.

Justin was discharged from hospital about two months later as he was gaining weight well, but Jordan stayed on in the NICU until 24th February 2004 when he was discharged. But he went back to the hospital a fortnight later because he was not breathing properly. From then on, he became a regular at the hospital. He would stay for a week or so and be discharged. But it wasn't long before he was admitted again. Back and forth, we would go to the hospital and home. Nurses and doctors got to know Jordan well and some became quite attached to him. Most people were very fond of my angel as he was a good baby, seeming to understand whenever others talked to him.

One night in May 2004, Jordan was coughing badly. I rushed him back to hospital with the help of my god sister Jennifer. His oxygen level had dropped and he was not breathing well when we reached the hospital. Doctors and nurses gave him oxygen and suctioned him immediately. As soon as he stabilised, he was admitted to the Respiratory Ward. Jordan cried nonstop and our hearts broke to see him suffer like this. The next day, they upgraded him to the High Dependency Ward. I have no idea how many buckets of tears I shed that day. Jordan cried for four straight hours and I was totally helpless. His chronic lung problems meant that it was very serious indeed that he had developed pneumonia. Doctors checked on him every hour and they finally decided to give him medication to help him sleep in order to rest both his weary, collapsed lungs. Shortly afterwards Jordan was admitted to the Children's Intensive Care Unit. By then, my world was shattered.

We never saw him awake again. In that month, he had gone through two major operations for his heart and intestine and several small procedures. He was also breathing through a strong ventilator. No matter how many times doctors tried, Jordan couldn't

wean off it. He even turned blue a few times right in front of me. There were three terrifying occasions when doctors had to revive him. All those needles and tubes in his tiny body (4 kg) were just too much for everyone to bear.

Every day during that month was stormy for us. But for the support I got from my family and friends, I wasn't sure how Martin and I were going to pull through. My mom did her best to tend to my two other little ones at home while Martin and I hung around the hospital watching over Jordan every day. My two brothers Adrian and Jun Bin visited Jordan after work every day no matter how late or tired they were. My other friends also gave us their concern and of course their blessings. My aunt and uncle even invited a highly respected monk to the hospital to pray for Jordan, in the hope of reducing his sufferings. Without them, Martin and I would not have overcome these difficulties.

On the morning of 19th June 2004, we got a call from the hospital at 5.00 am. Our angel was not doing well. They wanted us to go to the hospital immediately and instantly, I knew something bad was going to happen. On arriving, we saw several doctors outside his room and several nurses inside—Jordan was not going to make it. He left us almost immediately as I held his lifeless body and gave him my last kiss.

After taking off everything from his body, the nurses changed him into his own clothing brought by one of our best friends, Cecilia, who rushed back home to get it for us. Jordan's godmother, Ivy, Jennifer and her sister all rushed to the hospital to see him for the last time. I cuddled him and everyone there took turns to do so. We couldn't leave him on the cold bed. It was a heartbreaking moment for all of us there. I cannot forget how his body turned more stiff and cold by the minute. It was unbearable. Jordan had turned almost black when I laid him down at the casket company. We cremated him that very afternoon.

The next day, in the company of Martin, my mother, my brother Adrian, uncle, Ivy and Cecilia, we set Jordan free out into the sea. We hope he can start a new life free from sufferings.

Now he is in loving memory to a lot of people who have taken care of him or played with him. We hope he's happy in a good place called Heaven.

I still look at his photo every day and tell him I love him no matter where he is now. He will be in my heart till the end of time. This will not change because he is and always will be my son, my Jordan...



Kareem & Shakeel

Kareem Yeo
27 August 2004 – 5 February 2005
Shakeel Yeo
27 August 2004 – 6 February 2005

Kareem and Shakeel were born prematurely at 31 weeks and 15 minutes apart. We thought that it was only a matter of time before we could bring them home. Home they did come, only to leave us forever. After five months of struggling, we took them off life support, and said goodbye to our beloved twin boys one after the other.

Written by Aida Shariff, Kareem and Shakeel's mother

Roouf, my husband, and I were very excited when, at our first scan, we were told that we had twins. Raouf couldn't stop smiling and proudly told everyone he knew. The pregnancy went by smoothly without any complications, until my gynaecologist suspected that delivery might be early as there was too much water in both bags, and referred us to another hospital.

It all began on Saturday 22nd August 2004. I was bleeding slightly and then felt contractions during the night. On Monday morning, I was admitted to hospital as my cervix was dilated to 2 cm. They tried to stop the contractions but it didn't seem to work and my contractions got worse. They put me on a drip and gave me all kinds of stuff just to delay the delivery. I felt like a guinea pig being put on a test. I felt weak. I couldn't eat, couldn't sleep and I felt terrible. I couldn't bear these painful contractions and I just wanted the babies out. I told the doctors that I was ready to have them delivered but they kept fighting to delay delivery, warning me of the risks of premature labour. It was on Thursday when my cervix opened to 4 cm that they decided to have the boys delivered.

Kareem was born at 1917 hrs weighing 1.975 kg. I remember hearing a weak cry and I managed to have a quick look at him before they took him away. Shakeel was born 15 minutes later. There was no cry. He was tiny but at 1.68 kg, he was far bigger than many other premature babies. Raouf was not allowed in the operating room in case they had to do a C-section on me—I needed him with me so much and wished they had let him in as in the end, I had a normal delivery. Raouf was always there with me throughout my hospital stay. He cancelled all his flights just to be with me and went home only for showers. His presence comforted me and somewhat eased the pain.

I got to see my boys the next day at the Neonatal Intensive Care Unit (NICU). I remember feeling nothing. I was just glad that they had been delivered, had good weights and most importantly, they were stable. I tried expressing milk immediately as I knew the importance of breast milk especially for premature babies but nothing came. Four days later, I met the lactation consultant. It was an experience more painful than my labour but it got the milk flowing. I expressed milk three hourly religiously so that both my boys would have enough. After four months, I had to give Kareem formula on top of breast milk as I just couldn't express more than what I normally could. Kareem and Shakeel needed more each day. I tried my best to give them as much as I could. Shakeel got full breast milk while Kareem was on alternate formula. Raouf thinks I'm super as expressing milk every three hours was tough especially in the morning when everyone was fast asleep. To me it's what every mother would do for their babies. I couldn't feed while holding them in my arms at home. Most of their lives were spent in the hospital being fed by different nurses through tubes that went straight to their stomachs. The least I could do was to give them my milk.

Everything seemed to be under control in those early days. Although it was difficult to see their babies intubated and on ventilation support, it all seemed like normal premature procedures. There were various complications, but nothing major. After a month, Shakeel the younger twin was able to breathe on his own and so was released from the CPAP. Kareem was also doing well, but was still under an oxygen hood. Kareem had an infection and so the boys had to be separated in different ICUs. The following day, we were delighted when Shakeel was transferred to the special care nursery, and felt that he would soon be coming home. But two days later, he had a seizure, and had to return to the NICU. It was then that our hearts sank—we were told that our boys suffered from serious complications. They had jerking movements and when they opened their eyes, they didn't focus. Doctors suspected that they had a rare condition hardly known in Singapore. As some cases were known in Germany, there was a research lab in Germany willing to test the boys' blood to confirm the diagnosis, but as a research body, they had no obligation to run the tests immediately. There was nothing the doctors could do. They ran hundreds of tests, all of which came back negative except the thyroid test. Kareem had hypothyroidism while Shakeel had hyperthyroidism—but this was not a big problem, as it could easily be treated with medication.

We waited. Days turned to weeks and weeks became months. We still had nothing. All we knew was that Kareem and Shakeel were not normal, to what extent we didn't

know. Whether they would grow up to be normal or not, the doctors couldn't say. It was frustrating to get nothing when I visited them every day, hoping to get some answers. I began to feel afraid. How was I going to cope if my two sons were both abnormal? Through it all, I turned to God for strength and guidance. If it was meant to be for Kareem and Shakeel to be abnormal, I'd accept it as a challenge in my life. I'd love them all the same.

On 15th December, Kareem finally came home with a nasal canula for breathing. We took him to my mother's house as we needed as much help as we could get, particularly as Raouf was away so much flying. I also visited Shakeel in the hospital every day to take him my expressed breast milk. It was exhausting as I couldn't have more than three hours of sleep each day. Most of my time was spent cleaning the bottles, expressing milk, feeding Kareem every three hours and driving to hospital to see Shakeel. Even though Kareem was home, I felt I didn't have any quality time with him. The only time I had with him was when I bathed him, fed him or slept beside him. I was always doing something. There was no time for me to just take a moment and talk to him or just hold him in my arms. Something I wish I had been able to do.

Shakeel was due to come home on 20th December, but just two days before, his breathing deteriorated and he had to go back to NICU. Two weeks later, Kareem's condition also worsened and he had to be re-admitted to hospital. He had seemed more sleepy and was experiencing breathing difficulties. Imagine my disappointment as both my boys were in ICUs. We were back where we started.

Kareem went into the Children's High Dependency ward and the CICU the next day. His carbon dioxide retention was too high which was why he was always sleeping, so again he had to be intubated. During this stay Kareem was evaluated by another doctor, who concluded that his brain wasn't functioning, and that Shakeel would most likely be in the same condition. I was devastated. Questions ran through my mind, questions to which I had no answers. Why me? What have I done?

Less than a week later came the terrible news. Kareem and Shakeel wouldn't be able to survive much longer. Their lungs would fail more and more often. Every time that happened, they would be intubated and each time it would get harder for them to wean off. They would weaken and it would only be a matter of time before they perished. We were given two options. One was to continue to keep them on the life support system that they would need for the rest of their lives. They would be bedridden. They would grow physically, but would never develop mentally. The second option was to put them on minimal support, make them as comfortable as possible, spend time together as a family and let nature take its course.

I felt sad, disappointed, angry and lost. What should we do? Those were not options! That night, we prayed to God for guidance, to give us signs as to what we were supposed to do. We couldn't stop crying. The next day when we visited Kareem, he opened his eyes and suddenly his breathing laboured. This happened a few times. Each time, I could see that he was in pain. His eyes were telling me something. In that instant, I knew what we had to do. A few days later, we decided to have the two boys together in the same

room so that we could spend a day or two with them as a family before we started palliative care. We would try to make them as comfortable as we could and leave everything else to God.

When we told our family about our decision, they were very supportive. We even told Kareem and Shakeel about it. I remember telling them that if God wanted them back and it was meant for them to return to Him, then we were letting them go. We told them that we loved them and that we did not want them to suffer any more. We hoped they would forgive us if we had not done our duty as good parents. After we told our babies about our decision, Kareem no longer seemed agitated. He was calm and very peaceful. Shakeel was sleeping. We were at peace.

The day came when Kareem and Shakeel were wheeled to the special “Quiet Room”. I was happy yet sad. Both my boys were finally together but not on a happy occasion. We knew that the day was drawing nearer. We spent two days with our boys. During that time, we had family, relatives and close friends come to visit. I tried not to sleep at night as I wanted to spend as much time as I could with them. Something I shouldn’t have done as I needed to rest. On the third day, my body could not take it and I came down with fever. How could I fall sick at a time like this? My babies needed me. Kareem and Shakeel were put on nasal canula in the morning. At this point, there was no turning back. Should either one’s breathing deteriorate, we would have to let them go. That night, I vomited four times. I was so sick that I slept through the night leaving Raouf to do all the feedings. Luckily for him, the kind nurse on duty that night helped so he managed to get a little sleep. The next day, I felt better and we brought the boys home to my mom’s place.

Once home, we found ourselves so busy with feedings. It was chaotic. The boys had a lot of secretions and had to be suctioned before every meal. We tried to alternate shifts so that we could get some rest. Shakeel slept most of the time, but Kareem was in bad shape, turning pale quite frequently—each time we told him how much we loved him and said that if it was meant for him to go home to God we were willing to let him go. Every time we said that, his breathing stabilised. After two long nights, we woke for the morning feed but saw that Kareem was not moving. We thought it was one of those episodes and that he would be leaving us soon but what we didn’t know was that he was already gone. We called Raouf’s parents and told them to hurry down. My sister who is a nurse came shortly after. Once she saw Kareem she told us to call the doctor. It was only then that we knew he had left us. I was sad but somewhat relieved. I knew this day would come. I knew he would leave me and that I would miss him so much but I also knew it meant he wasn’t suffering anymore. He’s resting now and when the time comes, he will definitely go to heaven.

The doctor came and confirmed that Kareem had passed on. We proceeded with the burial immediately. Once everything was over, we focused on Shakeel. I felt sorry for him. We had been busy with Kareem and had somewhat ignored him. Shakeel was my beautiful baby who kept quiet while his brother left us so that we could settle everything without having to worry about him. After the burial, when everyone except our family had left, Shakeel started to turn pale just like Kareem did before he passed on. We knew then that Shakeel would be leaving us too. The next day after I fed him at 3 pm, I put

him on his side and I lay down beside him. Raouf was talking to me and suddenly noticed that Shakeel had his face down on the bed. I picked him up and realised he was lifeless. I knew he was gone. The night after his brother left Shakeel had tears in his eyes. The tears remained till he passed on. I supposed he knew he was leaving us and he felt sad. My only regret was that I hadn't spent enough time with him. Shakeel knew home for only three days of his life and even then we were always busy with Kareem. I hope he knows that I love him as much as I love Kareem. That he's my baby too. Every time I visited him at the hospital he was always sleeping so I didn't want to disturb him. Instead, I went to see Kareem who was always awake and agitated. So I spent most of the time calming Kareem down. I may have spent more time with Kareem but that wasn't intentional. I did whisper in Shakeel's ears a couple of times to tell him that I love him too. I also made it a point to give Shakeel full breast milk. I hope by doing so, he knew how much I love him. It was impossible to spend my time equally among my two boys but that did not mean I loved one more than the other.

I still cry every now and then, especially at night. I feel lonely; after the long struggle I suddenly have nothing to do. Despite the hurt, life has to go on. Kareem and Shakeel have taught Raouf and I a lot. That life is precious and unpredictable. We have learned to cherish our loved ones and see things differently. The sounds of children crying no longer irritate us. We longed to hear our boys cry—the breathing tubes they were on most of their lives affected their vocal cords so we seldom heard them cry. Even when they did cry, it was weak and soft. When I see little boys on the streets I see Kareem and Shakeel and wonder what it would be like if they were still around. It isn't easy to move on especially when your own mother keeps blaming you for what happened. My mom thinks I didn't eat right when I was pregnant and that the pills I took when I was carrying them caused their brain damage. But I did eat right, and those pills were multi-vitamins prescribed by my doctor. By blaming me, she makes me feel like I was a terrible mother.

Raouf is my solace—whenever I felt down he was always there for me. He took time off his work, has always been very supportive, and never once blamed me for anything. He helps me be positive. But I know he's hurting too.

Kareem and Shakeel have brought us closer to God—we believe they were sent to us to remind us of God's power; to bring us back on the right path. Neither of us were very committed Muslims before, but now we are doing our best to pray five times a day and learn more about Islam. We promised our boys that we would be good people and fulfil our obligations as Muslims so that we can meet them again in Heaven. Kareem and Shakeel are resting in peace now, and when the time comes they will be brought to Heaven. We know they'll be waiting for us there; we don't want to disappoint them.

The journey ahead will not be an easy one. We will constantly be reminded of Kareem and Shakeel. They will always be our babies and nothing can change that. Our plan for the future is to hope that we will be blessed with many more healthy children, to have a chance to be good parents, to take care of our kids and mould them to be good people who will be useful to society. We will definitely tell them about our babies Kareem and Shakeel; and how they were so beautiful and perfect that God wanted them home with Him.

SAYING GOODBYE ...

It is heartbreaking to have your baby die on you. It is gut-twisting when you have twin babies die on you. But our Muslim faith stood us in good stead when first Kareem and then Shakeel left us—all within 48 hours.

I wasn't a pious Muslim who would don the *tudung* and pray religiously. But I was aware when I became pregnant that I would have to set a good Muslim example for my twin boys. My husband is Chinese and was a Catholic. For our marriage, he had to convert to Islam and take on its full obligation of rituals and ceremonies.

When we brought the boys home after instructing the doctors to withdraw medical care, we knew that we had precious little time left as a family. Kareem breathed his last at around seven plus in the morning. According to Muslim law, the dead must be buried as soon as possible after all the rituals have been performed. The doctor was called in to pronounce and confirm his death, after which my brother-in-law dashed off to the police station to obtain a death certificate. With that in hand, it was then necessary to proceed to the cemetery to reserve a plot of land for our baby's burial. Raouf was new to the religion and was bewildered when his request for a neighbouring plot of land to be reserved for our other son had to be turned down.

Deaths are not predictable and, as Muslims, we have no right whatsoever to dictate the exact location of a burial plot, even if our sons are twins. That they could be buried together or next to each other would be possible only if they died within minutes or hours of each other. Our other son, Shakeel was still hanging on by a thread.

As a death is a communal event, relatives, friends, neighbours and even strangers would volunteer and delegate the various responsibilities of settling the burial rites among themselves. A small event such as offering a prayer even by a stranger would be welcomed in the Muslim tradition of death. Such was the communal nature of death in Islam and such was our situation when friends, relatives and even distant acquaintances turned up during our bereavement.

In the Muslim tradition bodies must be cleaned; even our little boy who, as a baby, was considered pure and innocent. Raouf, who all this time since the birth of his sons never had the opportunity to bath them because of his travel work commitments; bathed him, dabbed him with fragrant salts and gently patted him dry, taking care not to wipe the salt off. All dead bodies must be respected, even more so a little baby, so Raouf had to be extra careful and gentle with his son. Tender loving care was the key.

Raouf covered Kareem's body totally with cotton wool, then covered him with a robe and brought him out to the living room for everyone to kiss

him and say our goodbyes. Although our tears were flowing, we had to make sure that no tears must touch him as it is impure to do so. We then wrapped him in a big white cloth and carried him in batik to transport him to the cemetery. All this while, *the Orang Khairat Kematian*, the person who was in charge of death rites, was present throughout the proceedings. After final prayers were completed, Raouf then carried Kareem and took three steps with his right foot first out of the front door. Each step was alternated with a short prayer. Then, we made that last journey with our son to the cemetery.

At the cemetery, a smaller hole within a hole had already been prepared. Raouf placed our little boy down in that smaller hole, his body turned sideways facing in the direction of *Qiblat*—the direction in which all Muslims face when saying prayers. Then, a four-sided cover with no base was placed on top of Kareem. It is imperative that the body touches the ground for Muslims believe that we all originate from *tanah*—the soil.

As soil was being shovelled to cover the grave, we wept silently for to wail would have saddened his little soul, and covered his grave with flowers and then poured water around it.

Going home to Shakeel was hard after leaving his elder twin brother behind. As if by Allah or God's will, Shakeel might have known of his elder brother's passing and began to deteriorate gradually. But these hours were poignant as we turned our undivided attention to our younger son. All our relatives showered him with love, blessings and attention and then, on late Sunday afternoon, he too slipped away.

We could only proceed with Shakeel's funeral arrangements the next day as the burial office was closed. To wait out this period, we laid him gently on the bed and all of us took turns to chant the customary "*Surah Yassin*" prayers for our baby. However, grief and exhaustion overtook us and only one of my sisters managed to last the night. It is important for these prayers as upon recitation, all sins would have been forgiven. It was also a means of Allah lessening the agony of the departing soul. But Shakeel was a baby and did not have sins, so even though the prayers had to be said, we were very comforted that he had gone to a better world.

When day broke, we made the same arrangements for Shakeel as we did for Kareem, right down to making sure that his body was laid in the same manner as his older brother. As our little boys were babies, they were pure and had no sins. So we were heartened and gratified to know that they were guaranteed a place in heaven.

Our boys may not have been buried together or even next to each other but we could never forget how even in their pain and suffering, both were almost intuitively aware of each other's presence. We have lovely pictures of them reaching out for each other's hands and we most certainly know that even though they have left our side, they are together in spirit as twin brothers should really be.



Lily Belle Bilton
16 August 2004

Petrina and Tim are English expatriates who have been living in Singapore for four years. They had been trying to start a family for a long time and were overjoyed to hear that they had conceived twin daughters. Everything went well until a final scan at 38¹/₂ weeks could only find one heartbeat. Petrina writes of the mixed joy and sorrow she and Tim have lived through, experiencing one daughter's birth and the other's death at the same time.

Written by Petrina Mousley, Lily's mother

At lunchtime on Monday 16th August 2004 I passed by my husband's office to collect him on the way to what we had been told would be our final scan. I had reached 38¹/₂ weeks, full-term for carrying twins, still with no signs of going into spontaneous labour and our obstetrician had said he would do a last check before setting the date for a C-section on Tuesday or Wednesday.

Francis, the office doorman, waved us off having told my husband that the 16th was an auspicious day. There was a sense of excitement and anticipation and all should have been well with the world. In the taxi I remember saying that I just wanted to see Lily move on screen. She was lying across Isis and I found it difficult to sense her kicks had panicked me on a number of occasions. My husband reassured me that just as all the other scans had shown, both babies would be fine, dancing, kicking and interacting with each other.

As I lay on the scan table we chatted with our obstetrician as we always did. But

something about today was different. A general foreboding crept over the room which I put down to nervous anticipation. I was focusing on the obstetrician's face and could tell he was no longer fully engaging in polite chit chat. He was distracted and concentrating on the screen. I also knew, which my husband did not, that having located Isis' heartbeat, he was taking an inordinately long time to locate Lily's.

Something in his face confirmed my fear and my journey had begun. Having shifted positions several times to help him with the ultrasound as I knew she was in an awkward position, I told him he was really scaring me. I was desperate for reassurance but none came. He told me kindly that he had to find her heartbeat to reassure himself. It was at this point that my husband realised we were no longer dealing with an ordinary scan. The obstetrician advised us that we needed to get the twins out as soon as possible, that there was still a chance Lily could be ok but that we could take no risks. I staggered from the scan table, my legs buckled in shock and I felt sick to the stomach on a cocktail of dread, horror and disbelief. My husband and I were shown into a small side waiting room, to wait for a wheelchair to take me straight to theatre, and we collapsed into tears desperately trying to cling on to the hope that our darling Lily was ok. Within an hour I was in surgery.

Six months on in our journey, it is still too distressing to engage directly with the pain of our loss. It has been so confusing experiencing the highs of becoming first time parents when we are feeling such enormous grief. We have decided to let the following two excerpts tell the rest of our story. The first is from an email we sent to our closest friends on our return from hospital. The second is from a letter we wrote to our daughter.

“We are still reeling at the chain of events that led to the arrival of our two beautiful daughters: Isis Amelie Bilton (3.24 kg) and Lily Belle Bilton (2.5 kg).

In brief, having had fetal heart monitoring for both girls on Tuesday 10th August and Thursday 12th August, we were advised that both babies were doing very well with strong active heartbeats. On Tuesday we had agreed with the doctor that Thursday's appointment would be a final check before making the decision to take them out on Friday or Saturday, had I not gone into labour in the meantime. However on Thursday the doctor said that as the babies and I were doing so well we should wait over the weekend to give me a last chance to go into labour spontaneously. If we still hadn't had any signs by Monday, he said we would then make the decision to deliver them on Tuesday or Wednesday. It was at Monday's appointment however, lying on the scan table, when the fear kicked in. He was taking a long time to find Lily's heartbeat, two minutes rolled into five to ten minutes and still he couldn't find it. Shell-shocked we were rushed straight into surgery for a C-section under epidural. Tim was with me throughout—I couldn't bear for him to be alone with the news if indeed we had lost her,

and the doctor felt it would be better for me not to have to go to sleep not knowing and wake up still not knowing. Through all of this, that was the best decision we could have made. We both heard Isis cry the instant she was delivered and knowing she was safe, our focus went to Lily who was delivered two minutes later, stillborn. She looked so peaceful and so beautiful. Very like Isis with subtle differences. I had a big cuddle with Isis and then Tim went with her to the nursery to settle her in whilst I was stitched up. He then had some private time with Lily until the three of us were reunited, before Isis joined us. Our time with Lily was so precious. Holding her, talking to her—trying to understand why she had come so far only to leave us and her sister to cope with her loss.

So far there is no conclusive medical explanation, she was perfect, a good weight, a good size (the same length etc as her sister) and at 38 weeks gestation, full term for twins—the autopsy may or may not provide us with some clues but we will not receive the results for quite some time. Whatever happened was very sudden, as there were no signs of distress, which is a small comfort.

A friend got in touch with a child bereavement support group in Singapore and the following day two wonderful women came into visit us. They entered the room with open arms even though we had never met them before in our lives and we both agree we don't know how we would have got through the first few days without their support. It was like having family here.

We took photos with Lily and Isis, and thankfully we thought to take a lock of hair and hand and foot prints but we never got to dress her in the outfit we had chosen and the staff, although some were very sympathetic, still seemed very anxious to take Lily out of our room and off to the mortuary when we just needed her to be with us. We held a private blessing for her on Tuesday in the hospital to say our goodbyes and on Thursday her daddy went with her to the crematorium where she was surrounded by flowers from her immediate family. We will bring her home for a private ceremony at the church where we were married later in the year so she can rest in a place we love.”

Darling Lily Belle

We feel so blessed to have shared the nine months of your life. Your kicks and wriggles, your hiccups, your thumbsucking. We had such fun watching you grow inside me, scan after scan watching you play, move and develop. In spite of the sadness, it was a treasured moment to see you in the flesh on the day you and your sister were born. You were so beautiful you made our hearts stop. Our time together was so precious.

In my heart I feel as your mummy I should have done more, something, anything to keep you safe from harm. Please forgive me. I wanted so much to be your mummy. When I held you in my arms and saw your face it was the hardest thing I have ever done, to kiss you goodbye. We had so much love to give you and we will carry it with us always until in years to come we finally get to wrap our arms around you and breathe you in and share it with you once again.

We cannot express in words the sadness we both felt when the doctor delivered you and confirmed our worst fear. That the routine scan we had had that morning where he was unable to find your heartbeat had been right. You had already gone. Lily we are both so sorry that we didn't know you were struggling for your life. We are so sorry if there was anything we did or didn't do that would have made a difference. All we can ask for is your forgiveness. If only we could have our time all again, we would have delivered you earlier and then maybe you would be here with us and your gorgeous sister now. If only.

We held you tight in our arms amazed by your beauty; soft and warm milky skin, red lips and such a peaceful expression. It feels appropriate to say that you looked heavenly—like a small piece of heaven cradled in our arms, what an honour to hold you and spend two days with you. We wrapped you and felt the weight and warmth of you as we held you close. We studied your face, took a lock of your silky brown hair, your tiny fingers wrapped around one of ours and, if we closed our eyes for just a moment, the pain went away as your body rose and fell with our own breath as if you were sleeping and about to stir. How we longed for you to stir and yet they say never to wake a sleeping baby and you did look so so peaceful.

A mix of your mummy and daddy. We created you together out of love. And, in spite of the pain we will carry with us always, we are blessed to carry with us the memory of you. Those pregnant months; mummy stretched beyond recognition but still waddling so proudly, overjoyed by the expectation of having a family. How daddy had always longed to have twins—and what a treasured moment when we saw you and your sister for the first

time on screen at our scan and the news sunk in that his wish had come true. How blessed we felt.

We held a blessing for you and said prayer after prayer, clutching each other. Our tears wet your head and cheeks. You looked so much like your sister—two peas in a pod. We carefully chose your first outfit and, along with flowers from us and all your loving relatives, daddy took his first car trip with you—singing to you at the top of his voice so you wouldn't feel lonely.

The things that we would have shared with you: How painful to accept that we will not see your first smile or your first tooth. From two cots to one, our twin pram sits back in the shop window we first saw it in before the exciting day we brought it home and daddy spent hours “reading the manual” while mummy decided just to fiddle with every lever to make it work.

No words can describe the pain, the heartache, the devastation, the numbness, the loss that we feel. We have cried so many tears and still they keep coming. Part of our family has been ripped away—our own flesh and blood, our pride and joy, our future, our present—relief only comes when we shut out the reality of having you snatched away from us and yet denial leaves us sick to the stomach. It is all wrong. You are not here and we miss you, we miss you with a gnawing pain that won't go away.

Lily you were so wanted, so wished for, so anticipated, so loved. We would have had so much fun together. It is so hard but we are trying to understand why our time with you was so brief—and we are so grateful that we had the nine months we had to cherish you. That your sister is safe we are so thankful. What joy she brings us day after day. Thank you for keeping her company, inside mummy, and for helping her to stay safe on her journey into this world. It must have been hard to be parted. We will do our best to give her a happy, safe and loving home. And when she is older we will tell her all about you. There will be a lifetime of things to talk about when we see you again, but until then, sleep well our darling Lily Belle. Know, always, that we have loved you with all our hearts and we will go on loving you always.

Good night darling and god bless

All our love, your mummy and daddy



Lucas

Lucas Ethan Wong Kai-En
14 – 22 January 2000

Five years ago, Michelle and Patrick lost their second child Lucas to a rare genetic condition. It was a heartbreaking experience, and yet they feel that it has taught them many important things: about staying strong as a couple, about trusting in God and about truly valuing the gift of family.

Written by Patrick Wong, Lucas' father

The discovery

26th October 1999 was supposed to be a happy, exciting day for my five-month-pregnant wife Michelle and I. Already parents to 20-month-old Matthew, we were hoping that the ultrasound that day would reveal a little girl.

But minutes into our session, gender preference became secondary. The scan revealed that the baby boy was smaller than he should have been and that he had a cleft upper lip—telltale signs of a chromosomal disorder, the most common being Down Syndrome.

Our gynaecologist was sympathetic and reassuring. She explained our options—abortion being one of them—and advised us to think them over before seeing her in a week.

Devastated, we stumbled out of the hospital onto Orchard Road, the buzz of human lives cruelly ironic in the light of our discovery. But shell-shocked as we were, we both knew we had to make some tough calls—fast.

The first question: To terminate the pregnancy or not? Our unanimous answer: “No”. The next stumper: What to do now? We had no idea but we agreed immediately that we would face this crisis positively, proactively and as one.

We surfed the Internet and visited the libraries, gathering whatever information we could about coping with a Down Syndrome child. Our aim was to be prepared but keeping ourselves busy this way also forced us not to wallow in misery and self-pity.

But we were soon dealt another blow, more demoralising than the first. The next scan confirmed the baby’s poor growth, leading our gynaecologist to suggest that he had either Patau’s or Edward’s syndrome—both almost certainly fatal.

So just when we had psyched ourselves up for life with a “special needs” son, we now had to readjust to the terrible prospect of our baby’s death.

Coping together

How do expectant parents respond to news like this? How does a couple deal with the sudden plunge from hopeful joy to a whole range of difficult emotions: despair, fear, anger, denial, helplessness?

No doubt about it, a crisis like this can test and strain a marriage, or it can strongly reaffirm its foundations. Michelle and I coped by holding fast to our earlier pact: to face this test together, whatever lay ahead.

And this single-minded commitment to each other—and to the family we were building—served us very well in the months ahead.

But it was not smooth sailing. Such an ordeal can put emotional barriers between spouses. For one, there is the temptation to blame yourself or your partner for the situation, because it is natural to try making sense of your confusion by pinpointing a “culprit”. Or you could give in to hopelessness by retreating into self-pity, abdicating all decision-making to your spouse.

While both reactions may be understandable given the circumstances, you cannot remain a slave to them. The best way to tackle these private traumas is to keep communicating with your partner.

Michelle and I had conflicting views and emotionally-charged debates about choices we had to make but we made the effort to understand where each was coming from. More importantly, we had to always look at the larger picture and agree on important issues.

At the heart of every decision we made was our shared desire to celebrate our baby’s *life*. From what the gynaecologist told us, Michelle’s body should have rejected the foetus, given the probable extent of his genetic disorder. So the fact that he was alive inspired us to be positive.

We decided to give our baby an affirmative name: Lucas Ethan—the first meaning “bringer of light”, for opening our eyes to the silver linings around the clouds; the second

meaning “firm”, for the strength he seemed to infuse us with. His Chinese name echoes the latter: Kai-Ren means “victorious in tenacity”.

Naming Lucas also allowed us to talk to Matthew about him in concrete terms. Not yet two, Matthew was linguistically advanced, and even though he surely did not comprehend everything, he understood that Lucas was his little brother and part of our family. That meant a lot to us.

Helping hands

But no matter what private coping mechanisms are in place, no couple is an island. Never discount the importance of seeking support and solace from others: God (if you are religious), family, and friends.

Michelle and I were blessed with many “ministering angels”. Besides finding solace in prayer, we also had the sage advice of a priest who lifted our drooping spirits: “Don’t despair,” he said. “I believe God gives special children to special parents who have the strength to cope.”

Our parents and siblings took the news bravely and gave us their unconditional backing. They would leave the key decisions to us but made it clear they were ready with help—emotional, logistical, financial—whenever we needed it.

We also found consolation in our friends and colleagues. They offered advice and commiseration, and spoke of our fortitude, which helped us persevere.

And in my cousin and his wife, we had a stirring example of how to cope with bereavement as parents. They had lost their toddler daughter suddenly just two weeks earlier, and together with their families showed amazing acceptance and courage despite their obvious grief.

Ups and downs

If the months leading to Lucas’ birth were testing, the week that followed it was a stressful roller coaster of highs and lows.

He was delivered safely by C-section but was immediately rushed to neonatal ICU even before either of us had a chance to look at him. But the good doctors had their reason: his vital organs were struggling to function.

More than once over the next few days, Lucas’ fragile system collapsed and was revived by the dedicated ICU team. We steeled ourselves for the worst, then despair turned to relief when his condition stabilised and tests revealed that he had neither Patau’s or Edward’s Syndrome.

But any flicker of hope we harboured was soon extinguished completely. Further tests revealed that Lucas had significant genetic material “missing” on chromosome four. The condition was fatal, after all.

farewell, my child

We drew close and prayed. We registered his birth and had him baptised. We visited him twice a day. Unable to cuddle him because of all the life-sustaining tubes attached, we stroked him, read and sang quietly to him and told him what a fighter he was.

After a week, my wife and I decided not to delay the inevitable. We set a date and time for Lucas to be taken off life support—it was the hardest choice either of us ever had to make, involving lots of discussion, soul-searching and tears.

It was another priest—the one who baptised Lucas—who again put things in perspective for us: “Your decision to let Lucas go is not a betrayal. You have already done the right thing by giving him your love and the chance to be born.”

So the next day, as the doctors gradually lowered the life support, and with our families around us, we finally got to hold Lucas in our arms as his little life ebbed away.

The year after

Lucas’ wake, funeral and cremation were emotionally draining but at least we were surrounded by family and friends.

The full pain of our loss—that aching emptiness—only hit us later. Our home seemed strangely barer, even though Lucas had not actually lived in it. The real gap was an emotional one and the grief took a good year to subside.

At the start of that period, we were asked by the doctors who took care of Lucas to help initiate a support group for bereaved parents. They felt that we had coped admirably with the situation and that we could share meaningfully with couples going through a similar ordeal.

We considered it for a few days but eventually declined. While we felt that this may have been a call from God, via Lucas, to minister to others, we were still feeling the pain of the experience too keenly.

Refocusing on Matthew—who, unfortunately, had to take an emotional back seat during those difficult months—helped us to heal. We started appreciating him with a new depth, cherishing every moment with him much more.

Needing time and distance away from it all, we took a family holiday in Australia some months later. We had a great time, and started feeling that it was all right to be happy again.

Becoming parents again (and again!)

But even though our lives gradually returned to normalcy, there was still that gaping hole that Lucas’ passing had left.

This was felt especially acutely by Michelle. Make no mistake—my wife is an incredibly strong person (stronger than me in so many ways), but the loss hit her very

hard. She desperately wanted to conceive again, not so much to “replace” Lucas, but to resume building our family.

It took us just over a year before we were successful again. It was a stressful period of trying and failing (odd, because conceiving the two boys had been a cinch), but we finally got good news in February 2001. And the news got better some months later: “You’re going to have a princess!” our gynaecologist announced.

To say that I was ecstatic would be a huge understatement. I had always wanted a little girl and according to Michelle, I wore a huge grin for weeks after the news. But more than joy, there was also a great sense of thankfulness in us, especially after each scan that showed how well our girl was doing.

Sara arrived in November 2001 and our family felt complete. Matthew continued to amaze us with his powers of speech and reading, while Sara thrilled us with her easy ways—she ate voraciously and slept through the night at eight months old.

Still, God had one more surprise for us: the unplanned conception of our third son Zachary. Born in June 2003, he has added another dimension to our lives by proving to be a “quick mover”, with his hyperactive dashing around the house and eagerness to scale anything that looks climbable.

It is sometimes tempting to see Zachary as a divine gift, a heavenly “substitute” for Lucas. But if there is one thing we have learnt, it is that each child brings different challenges but each child can also bring different blessings—if we are able to see these challenges as blessings.

And that neatly sums up Lucas, the little boy who lived for just eight days but whose brief life brought so much new meaning—and closeness—to ours.

God's Lent Child (excerpt)

We will shelter him with tenderness
We'll love him while we may
And for the happiness we've known
Forever grateful stay.

– Anon.



Max

Maksim Tadeusz Szpojnarowicz
5 May 2000 – 17 April 2002

Chris and Sonya are English expatriates who have lived in Singapore for nine years. Max was their first child, a beautiful, happy, healthy little boy who brought them enormous joy. Their lives were turned upside down when Max suddenly died, peacefully, in his sleep just over two weeks before his 2nd birthday. There was no warning—he had only shown “normal” cold symptoms for a few days. Sonya tells of the agonies of their grief and their determination not to lose hope, and shares the eulogy she wrote for Max’s funeral.

Written by Sonya Szpojnarowicz, Max’s mother

I was so happy when I first discovered I was pregnant. I had been keen on starting a family for a while, but had been going through a miserable and unsettled time while my mother in England was very ill and I spent nearly five months taking care of her in a London hospital until she died. Max’s conception a few months later brought me a new joy and optimism and I revelled in my pregnancy, enjoying every new sensation and making a point of nurturing myself and this precious new life.

Our beautiful firstborn son was born on his due date, 5th May 2000, a Millennium baby and a golden dragon—everything seemed so special and so full of promise.

He was a healthy, active little boy, always looking pink and radiant, energetic and nearly always smiling. He was an “easy” baby, a joy to mother, a very special child. He was so good-natured, sweet, kind, patient, cheerful, friendly and happy. He loved his life

in Singapore. He loved his home, his toys and his cat, his friends down the road. He always attracted a lot of attention from the locals in Singapore as he was so blond, with such big blue eyes and a typically cherubic smiley face. He was always friendly, trusting and interested in people. He particularly loved people coming round to our house, whether they were friends he knew or visitors he didn't or even the postman and the dustmen, all of whom he rushed to greet with a delighted "Hello, hello, hello!". When people came in, he would bring them his toys to play with and show them his books, and loved singing his favourite songs to them—especially "Baa Baa Black Sheep" and "The Wheels on the Bus". Singing was one of his favourite things, and our house was always full of singing and dancing and music. We used to make up silly songs or change the words for a joke and we probably had a song for almost every situation.

He was a very good little boy, who never did anything intentionally bad. Probably the naughtiest thing he ever did was drop a few peas on the floor from his highchair with a cheeky grin on his face, looking to see how Mummy would react. Friends would talk to us about disciplining their children, telling of "time outs" and tantrums. We would always shake our heads and almost be embarrassed to say that we never even had to think about any of this with Max, although we would always postscript this by saying that we were sure that the "terrible twos" were just around the corner. But Max never got to turn that corner.

He was delighted with his new baby brother Lukas when he was born in December 2001. We had been breaking him into the idea with a couple of books about new babies and one in particular with photos of a baby growing from newborn to toddler was a special favourite. He used to help rock Lukas's chair and bring him toys to play with, shaking rattles in front of him to make him laugh. He loved it when he and Lukas bathed together and when they had milk together.

His language skills were increasing rapidly. He loved counting the stairs with us. He was just beginning to string words together to try out sentences—"Sit down baby", "No bite a Mak" (said to mosquitoes). Rather poignantly, his last new words and phrases were "new day", "bad cold" and "heartbeat".

In April 2002 he came down with a cold—nothing particularly bad or unusual but one of those toddler colds which made him a bit quiet and miserable with a runny nose and reduced appetite. But he had had things like this before and always fought them off, so we weren't worried. He had cold symptoms for five days, but during this period, he still had a good time. My husband Chris had been away for a week, coming back on Friday evening and we had an especially good weekend. On Saturday we bought Max his first potty (which he kept sitting on proudly with his clothes on in the shops), went to his beloved Bird Park and then later to Raffles Marina for a party. We stayed late into the evening, Max revelling in the attention from everybody there, rushing off to see the moon and stars and tell everyone where his boat was. He had a particularly exciting evening as when we eventually got back to the car it failed to start and we ended up going home in a taxi which he found very funny. The next day our friends held a children's

party to celebrate the Cambodian New Year and Max loved playing with all the children in the garden, especially as the little boy there had just got a new trampoline. We had a close, happy few days as a family.

Then on Max's last day, Tuesday 16th April, he went to his gym club in the morning with Chris and jumped excitedly on his beloved trampolines. In the afternoon, he felt a bit sorry for himself and sat on the sofa watching his favourite Teletubbies with Lukas in his baby chair beside him, while we moved furniture around. He didn't really want any dinner and had some diarrhoea, but then he perked up at bathtime and played and splashed with Chris, and drank all his milk at bedtime. We all kissed goodnight.

I went in to check him as usual at midnight, and he had a bit of a fever. We debated waking him to give him some paracetamol to bring it down but decided he needed sleep more than anything and left him in peace. We put the baby monitor on as usual, and turned up the volume to full in case he woke up in the night with his fever.

Then in the morning, when we woke, he was still quiet. We were pleased, thinking he was having a much needed lie-in. We made plans for the day and I said I'd take the boys to the Zoo rather than go to Max's usual playgroup at St. George's as he was probably infectious. Then when I eventually went into his room to wake him, the world caved in around me. He was dead in his cot, lying cold and stiff and face down. There are no words to describe the feelings whirling around my head all at once. It was so obvious that he was dead—but how could that possibly be???? His body was there but the spirit and essence that was Max had gone. I will never forget those painful images.

An autopsy was done, which concluded that Max's death was "consistent with viral pneumonitis". Nothing is proved conclusively as they didn't manage to culture any viruses but it seems that Max's lungs were attacked by the virus and so compromised his breathing—although there were no visible symptoms of this other than the seemingly normal cold symptoms. So many other children in Singapore had what seemed to be the same virus at the same time but for some completely unexplainable reason, Max was unlucky. His lungs succumbed even though he was in every other way, a completely healthy, fit, strong boy, at the top of the scales for weight and height.

I don't really know how I got through those terrible days, weeks and months. A large part of me wanted to die with Max. I couldn't bear to face reality—the reality which I had always thought I'd known had been thrown into disarray and chaos. The pain of the loss, shock, grief, rage, horror, disbelief was heartbreaking, soul-wrenching, spirit-breaking. I remember that it was unseasonably and dramatically stormy for a while—dark skies, howling winds, pouring rain, thunderclaps—this felt so right—the world was turned on its head and was howling with grief alongside me.

We were lucky in that we had our second son, Lukas, who was four months old. He was quite literally our lifesaver. He took away any choice—he was our beautiful and deserving son and he needed us—and we loved him. I was breastfeeding him so I made myself eat, drink and rest so that I could keep going. But it was very, very hard.

We decided to make many things in our life different to help us get through the days—Chris was due to start a new job at a new company anyway, and we moved to a completely different house in a completely different area.

Nearly three years have passed since that terrible day. And we are still here. I will always wish passionately that things weren't the way they are, always feel a desperate yearning for my first son—as if there was a big “P.S.” after everything we ever did or said—“BUT MAX IS DEAD”. But life just keeps on moving on. Lukas is now older than Max ever got to be and our family has grown with our third and fourth sons, Jakob and Kaspar. We still miss Max every day, think about him, talk about him (Lukas loves to see pictures of Max and to talk about things he used to do)—but we are also able to be happy.

A funeral was held for Max at St. George's Church, Minden Road, where I used to take him to weekly playgroup for all his life apart from his time in Holland. It is a very welcoming, family church, always full of children. The children from the playgroups all painted butterflies to decorate the church and wrote messages on them. This is the eulogy I wrote for Max which was read at the funeral by our dear friend Andrew:

Max Means “The Greatest”

From the moment of his conception his life was bursting with great joy and great promise. Before he was born he crossed the Equator on a sailing boat to celebrate the new Millenium; he holidayed in Australia, Thailand and Hong Kong and he lived for a while in a beautiful flat in London next to Greenwich Park. Even his date of birth was special—the 5th of the 5th 2000, a day when five planets were momentarily in line. He was born in Singapore and lived there for three quarters of his too short life, and for six months, he lived with us in Amsterdam looking out over the beautiful Herengracht canal.

He saw snow—real in Holland, foam in Singapore. He laughed at the world from his favourite seat on the front of our bicycle and cycled through tulip fields and by the sea in a glorious Dutch spring and then later in East Coast Park, Sentosa and other local haunts. Every Saturday, his proud Daddy would take him cycling—no matter where, as they both just loved being together on the bicycle. He holidayed on Tioman and Sibul islands, in Spain, Cambodia, the Cameron Highlands, Langkawi, Vietnam, Desaru, England,

Holland...Perhaps his favourite was playing in Angkor Watt with two little Cambodian girls and climbing delightedly over the ruins and tree roots which were to him an enormous playground.

He was only just beginning. He took great delight in his rapidly expanding vocabulary and repertoire of songs, and was just entering the world of letters and numbers and colours. Nearly every day he had a new word and loved using it again and again and again. He was always singing. He greeted everybody and everything he met with a heart-melting smile. You couldn't help but be won over. He'd just got his first potty.

He had a very short life, but nearly every moment of his just over 700 days was filled with happiness, joy, love and laughter.

He loved his home, his car seat, his toys, his bedroom, his books and his pictures. And shopping trolleys, lifts, escalators, buses, trains and the beeps on the BBC World Service. He adored his friends, his cat; music, dancing and songs, his playgroup at St. George's, and the trampolines at Prime Gym. He loved visiting playgrounds, the Zoo, the Bird Park, the pool and his boat. And most recently of course, he loved his new baby brother, Lukas.

He loved us.

And he always knew how much we loved him.

Hardly a day went by when we didn't say to each other how beautiful he was, how much we loved him, how we wondered if all parents could feel the way we did. He enriched our lives beyond measure—everything we did with him was fun, special, even going to the supermarket became a fun-filled adventure.

Now everything we see makes us think of him and we feel such acute pain and intense agony that he is not here with us any more.

We want him back.

We will always want him back.

We are broken.

Crushed—not knowing how we will be able to pick up the pieces and start again.

Max has a beautiful baby brother, Lukas, who worshipped him and watched his every step with love and smiles.

We know we will rebuild our lives because of Lukas.

Lukas means “light”—and he will have to help light our way through this awful darkness.

But he will never again have his big brother Max to play with.

Max means “the greatest”. He gave us the greatest joy. When we thought of him we couldn't help but feel the greatest love, pride and happiness.

Now we feel the greatest pain, loss, anger, confusion, desolation and desperation.

But we hope that with the light that is Max's baby brother Lukas, we will one day be able to think again of our darling Max with the greatest happiness that he so much deserves.

Untitled

As I look up to the sky
I really wonder why
We had to let you go.

But I know where you are
When I look out for
And see your shining star.

There you are, and there you'll stay
Shining in the milky way
Far, far out of reach.

If I could have had a few last words
Speech would have left me like a flight of birds.
I wouldn't have known what to say.

You'll always have a place, a part
Deep inside my troubled heart
Where you'll never leave.

– Jessie Opio, Sonya's god-daughter (aged 12 years)



Ning

Lee Shan Ning Eryn
8 August 1998 – 31 December 1999

At a time when most people were eagerly awaiting the new millennium, Valerie and Gerard were abruptly silenced by the death of their darling daughter, Ning. What appeared as a simple flu turned fatal almost overnight. But with deep faith and family support, they slowly found strength to appreciate life again.

Written by Vanessa Baxter, from an interview with Valerie Lim, Ning's mother

Valerie Lim was a typical first time mother. Elated to discover she was pregnant Valerie opted for a natural birth that was much easier than she expected. “Eryn Lee Shan Ning” was born on 8th August 1998, weighing a petite 2.8 kg and measuring 48 cm. Arriving with extraordinary ease, Ning exuded gentleness with her soft features and sparkling eyes. She grew to be a happy child who enjoyed the company of her family and friends and was cherished by all in her extended family. As familiar with her maternal Grandmother as she was with her parents she grew in her first year surrounded by faith and love. Ning’s first spoken word was “Papa” and a favourite spot for play was a tent pitched in the living room! Val and Gerard treasured their family moments and felt blessed to be her parents. Whilst Val loved her job at The Esplanade, she resigned on 15th December 1999 so that she could spend more time with Ning.

A week later on Christmas Eve, Ning showed signs of a fever, which her parents treated with the usual medication. The fever under control, the family spent a quiet

Christmas at home while Ning happily played with her new toys. On 29th December, Ning's fever rose to 39.5°C and at midnight her concerned parents hastily drove her to Gleneagles Hospital. Within a couple of hours her fever had escalated and she lost consciousness. An ambulance rushed her to NUH for specialised care. Tragically the virus that resulted in the fever had attacked her brain stem and her body organs shut down. By midday on 30th December 1999, Ning was on life support and medication which could not be sustained. At 7.10 pm on 31st December, Ning passed away peacefully having never regained consciousness.

The cause of Ning's death was certified by the coroner to be viral encephalitis. How she contracted it remains unknown.

The bond of strength amongst family and friends was evident in the days following Ning's death. People spontaneously assembled and assisted with arrangements for the funeral. Bouquets of white flowers and baby balloons were ordered for the wake and music was selected for the Mass. Aunty Pam sang Ning's favourite lullaby "Circle Game" and her best-loved uncles and Papa carried her to rest.

As others celebrated the turn of the century, Val and her family faced an enormity of loss that was indescribable. Overwhelmed, stunned, and numb, Val questioned over and over, "Why is this happening to me?" She could not accept that the timing of Ning's death was a coincidence and felt a powerful message was hidden in this tragedy. Her private feelings of guilt consumed her and she questioned whether she had in some way failed Ning as a mother. Waking daily to her own tears, Val felt the reality of her empty home and her lack of purpose. With no external, independent support mechanism available at this time Val turned to her faith, her family and her friends for stability and support. Through prayer and in asking God's guidance Val was learning to accept her daughter's death but without a concrete answer to her questions.

Meanwhile, her family was gaining a strength and closeness grown out of mutual prayers and a search for peace. Gerard took time away from work and along with their own parents, he and Val travelled overseas. Together they visited holy sites and historic locations to appreciate the majesty of life and God's creation. Each had moments to reflect on their lives and the life that had been so quickly taken from them. This was a turning point for Val who realised she needed to stop searching for answers and to relish the peace imbued in sacred places like Churches and to harness this peace for herself and Gerard. The trip was a moving and bonding experience for a family who came to be whole again. Together, the family now commemorates special occasions such as Ning's birthday and the anniversary of her death. These rituals of coming together to celebrate Ning's memory provide a way of incorporating the deeper meaning of her loss into their own life experience.

Val's friends surrounded and supported her when she desired company but allowed her to grieve in private on request. Their children gave Val the hope that she would be a mother again. She would "steal" hugs from children Ning's age to imagine her little

daughter at her side. Slowly Val gained strength to divert her energy to meaningful activities. Children's Voice, an annual fund-raising project set up with friends in the midst of these dark days, is one of many children's charity projects that Val is now involved in. She feels blessed to have learned the joy of putting others before herself, a lesson Ning helped her to grasp.

Gerard was one of Val's greatest sources of strength. Whilst grappling with his own grief Gerard was always able to attend to Val's needs and in doing so he too gained an inner strength for healing. They would discuss each other's feelings and fears and found an openness and mutual understanding that brought them even closer together.

The year 2000 was humbling. God took and God gave. Ning's funeral engulfed the beginning of the year and then Val discovered she was pregnant. Thrilled and thankful Val also worried for the baby she was carrying through such an intense time of grief. Weeping and dreaming about another girl, Val tossed between sorrow and joy. On 1st December 2000, she was elated to give birth to a stunning little boy, Lee Ze Ning, known as Noah, a "gift" from his sister with her eyes and a wealth of worldly wisdom in his boyish looks. Two years later, Lee He Ning (Toby) was born and Val considers herself a Mother blessed with three extraordinary children, one who watches over them all.

Val talks to her boys about Ning, an important part of her own healing process. She creates stories for them about Ning's adventures, shares videos of Ning with them and displays her photographs prominently around the home. The boys share in the memory of the sister who came before them and they know that she is not with them today because God asked her to go home to Him early and she obeyed. Praying together, laughing at Ning's antics, sharing her special moments and simply remembering her is a crucial part of this family's ability to move on.

It has been five years since Ning left to be an angel. Never a day passes without Ning being remembered and loved. Whilst we should not wallow in the past or submit to our memories, we should always search for a way to value them. Treated as a treasure these memories can give lasting pleasure, comfort and inspiration.

An angel has passed.
In the rippling of her wings
She touches our lives.

Heavenward.
Go little one, fly.
We will never forget.

– Joanne Cacciatore
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Ryan

Ryan Tan Jia Wei
27 February 2000 – 1 July 2004

Ryan had been enjoying himself at a poolside party minutes before he was found unconscious in the pool. He died 12 days later from drowning. Shattered by this tragic accident, his parents Jeanne and Nick, and his older brother Russell struggle to carry on and make sense of life without the baby in their family.

Written by Sonya Szpojnarowicz, from an interview with Ryan's parents Jeanne and Nick

On Saturday, 19th June 2004, four-year-old Ryan excitedly accompanied his parents and his big brother Russell to a party at his father's friend's place. They had been there before, and as they knew the party was to be around the condo pool they had talked about taking swimming things with them. The boys said they weren't interested in going to swim as they wanted to chat to their friends and enjoy the party, so they didn't take anything.

Everyone enjoyed the party. It was a beautiful setting and the place was brightly lit as evening fell. People were standing around in different groups chatting and enjoying the atmosphere. As some children were swimming, friends offered to lend the boys their spare swimming clothes if they wanted to join in—but again the boys said they didn't want to as they were quite happy playing outside.

Ryan's mother Jeanne was sitting near to the side of the pool, chatting with some friends. Ryan decided it was a great game to run loops around the pool, coming back to report to Mummy each time. He would dart off laughing, and run back calling, "Hello Mummy!", very pleased with himself.

But this time he had been longer away than before. Jeanne was beginning to look around for him, wondering where he was, assuming he had been distracted by someone else—but not imagining that anything was wrong. Ryan's father Nicholas was chatting to some friends at the other end of the pool when he heard a child scream out, "Hey look! Someone's drowned in the pool!" Never for a second imagining that this could be his own son, he rushed to look, and could indeed see a small shape underwater. "Maybe it's just a towel," he said, trying to calm the child. But another friend had realised that this small shape was a child, and dived in to grab him out.

In a split second Jeanne and Nick's world was turned upside down. Their beloved son, who moments before had been running around laughing, having a great time at a family party, was lying unconscious before them, not breathing and not moving—nobody could believe that this could really be happening.

Nick is a trained first aider through his work as a cabin steward with SIA, but he had never thought he would have to use his skills on his own son. With the help of a friend he tried to resuscitate Ryan, and an ambulance arrived in minutes. Both Nick and Jeanne wanted to accompany their little boy to the hospital and were shocked to hear the staff say that only one parent was allowed...but how could it be possible for any parent not to be with their child at such a moment? In their desperation they both got in anyway, but their hearts sank as they realised the two paramedics were only inexperienced NSmen, and they were putting the oxygen mask on Ryan's face upside down... The ambulance journey felt like a nightmare that seemed to take forever—Nick and Jeanne both felt paralysed with panic, shock and terror. They could hardly register the young paramedic trying to get them to fill in their IC details on the forms as they tried to focus on their beautiful young son's face, to hold his hands, hoping desperately that everything would be all right.

At the hospital Ryan was resuscitated but remained unconscious, and was taken to PICU where he was put on a ventilator. The doctors warned Nick that the prognosis was not good, but they would have to wait and see and hope. Nick and Jeanne stayed at the hospital, while Jeanne's sister looked after Russell, sleeping in a room on the ward, spending every waking moment with their beloved son. Friends came to visit and to give support, and many of their friends from Church came to pray. Russell was allowed to come in to see his brother, but it was a very difficult experience for him to see Ryan not moving, attached to so many tubes and machines. It was all so hard to take in—Ryan looked so normal, so peaceful.

For 12 days the family lived a scarcely bearable nightmare of desperate hopes and terrifying fears, waiting for something to happen. They had sickening conversations with doctors about the possibility of taking Ryan off life support, or of Ryan surviving but being severely handicapped. What kept them going was that Ryan really seemed to be responding to them—tears would flow from his closed eyes when they spoke to him and stroked his hand, or a dangerously low brain activity reading would normalise when they kissed him and told him they loved him. They had to take each day as it came, never knowing what was going to be the outcome, but scarcely daring to hope. One terrible day Ryan suddenly swelled up, full of fluid, which the doctors said was normal in such a drowning case—but then the swelling subsided and Ryan looked beautifully “normal” again.

But very early in the morning of 1st July, Nick and Jeanne had to watch helplessly as Ryan gently but surely slipped away. He died as they sat with him, crying, telling him they loved him forever.

Nick and Jeanne were thrown into a new and frightening world, trying to deal with their own agonising pain and grief at the same time as keeping life going as “normally” as possible for their eight-year-old son Russell. This story is being written less than a year after Ryan’s death—his family have had to endure their first Christmas and New Year without their younger son, and their first Chinese Lunar New Year. Before this book is printed they will have faced what should be Ryan’s 5th birthday. They struggle on, gaining strength from their Christian faith which reassures them not only that Ryan is in a happy place but also that they will see him again. Jeanne reads as many books on grief as she can, and writes her thoughts and sorrows into letters and poems for her beloved lost child. Nick is strong, open and honest, talking eloquently and sincerely about his grief, willing to share his feelings with compassionate friends. They are doing everything they can to face their grief and to try to keep living as a family, to keep hoping that in time they will begin to be able to enjoy life again. But it is a long hard struggle that is only just beginning.

Three months after Ryan’s death, his mother Jeanne wrote this poem for him:

I Remember

I remember—your first butterfly kick in my womb,
I remember—my tears of joy when your naked slimy
 little body was placed on my chest,
I remember—your first angelic smile that brought
 so much joy to our lives,
I remember—the first brave step that you took,
I remember—the first time you called me “Mummy”,
I remember—the time you had your first little tooth,
I remember—loving and caressing your tiny body sleeping beside me
I remember—my high anxiety when you fell ill
I remember—the sound of your little feet that greeted me every morning
I remember—our bedtime “chit-chat”
I remember—the adorable angelic look on your face,
I remember—whispering sweet nothings to you in your sleep,
I remember—loving your sweet sweaty smell,
I remember—your cheerful greetings of “good morning”, “good night”, “I love
you”,
 “take care”, “drive carefully, have a nice day” and many
 more of your loving care.
I remember—the hugs and kisses, the warm smooching,
I remember—my wonderful companion when Daddy was at work
 and kor kor was at school,
I remember—the precious time we shared when we were alone,
I remember—you singing Robbie Williams (“Better Man” and “We Will
 Rock You”),
I remember—you watching “Jamie’s Kitchen” with delight,
I remember—you imitating “Sponge Bob” with excitement,
I remember—how you enjoyed shopping and outings,
I remember—how your “Mummy you look so pretty and you
 smell so good” made my day,
I remember—you jumping into my arms and giving me a bonus hug and kisses
I remember—my little kitchen helper busy beating eggs for me,
I remember—how obedient and patient you were with me,
I remember—the excitement in your voice when you welcomed Daddy
 and kor kor home,
I remember—our daily tea breaks—milo and your favourite ah ma’s biscuits,

I remember—you holding ah ma's hand lovingly wherever we went,
I remember—your sweet hello's to all the strangers you met,
I remember—the joy you brought to everyone who came in contact with you,
I remember—the fear in your eyes on your first day in school,
I remember—you sharing with me the fear of going to school,
I remember—the tears you shed when you were angry,
I remember—the shouting match you had with kor kor,
I remember—how you and kor kor filled our house with so much life, love and joy,
I remember—thanking God for having you, kor kor and Daddy,
I remember—the bubbly and cheerful boy who lit up my life,
I remember—both of us cuddling and lazing around on a hot afternoon,
I remember—worshipping every word you said,
I remember—with you, I started to love all over again,
I remember—how colourfully you painted my life
I remember—every second, every minute, every hour of the four years and four months we shared together.

And how can I ever forget the shock,
The anger, the fear; and the
Overwhelming pain when we said our first and last goodbye.
My precious possession and part of my life has been snatched from me,
I am acquainted with bitterest grief.
I am crumbled, my wound is permanent,
My soul has been badly tormented,
My eyes blurred with tears.

Now, my life has changed forever.

AND I WILL ALWAYS REMEMBER...



Sascha

Sascha Daniel Frazier
14 July 1997 – 14 February 2000

Before Kendra Frazier moved to Singapore in 2004 with her family, they lived and worked in India. Sascha was the beloved youngest of four children. Their happy lives were shattered when three-year-old Sascha suddenly died, going into shock from the side effects of what seemed like a normal cold. Kendra describes how she has struggled to find meaning in the midst of the agony.

Written by Kendra Frazier, Sascha's mother

To tell Sascha's story would take a lifetime, because it was a lifetime—a short but precious one. And what is “short” or “long” in terms of all eternity? His lifetime was an entire lifetime, just like anyone else's. I knew him from the moment of his conception deep inside me, I witnessed his first breath on planet Earth and held his hand when the last breath escaped his lips, releasing him to other realms. His life touched mine uniquely and profoundly. My life was changed irrevocably when he was born and irrevocably, yet again, when he died. So, when I think of what to say about his life (and mine) I wonder what I can write in just a few words that could do justice to the relationship of a lifetime.

The details of his death, I realise in retrospect, are not as significant as the fact that he lived and that he died. But, at the time, these details consumed my thoughts and energies: he had had a cough for a few days, but was doing better when we put him to bed that night. Later we heard him crying and coughing, and when we went to him he

seemed to be choking on his own phlegm. Apparently a piece of mucus then lodged itself in his lung like a plug, and in that moment his lung collapsed. He went into shock and stopped breathing... It was sudden and unexpected, a simple cold gone wrong, no real explanation, a lack of air, a heart stopped beating, the world came to an end. That's what it felt like: I remember the terror, the horror, the unbearable sorrow and despair that sent me falling into an emotional abyss. I stayed down there a long time, wishing my own breath would fail me and that my own heart would cease its painful beating. Stop! Stop! Stop! I cannot bear this! No parent can bear this! Not this!!!!!!! Not my Sascha!!!!!!

One of the first people I called after Sascha died told me, "He has given you a great gift." For a second, before I plunged back into bottomless depths of sadness, those words spoke to me and made me think. Could losing a child bring anything other than despair? I revisited this question again and again and again over the years and, slowly, with time, I began to understand the inherent wisdom of my friend's words. To witness the birth of a child is a wondrous event, but to view his or her lifeless body (a body one has nurtured and loved unconditionally) is an event of such magnitude that one cannot comprehend it. Or, rather, one can spend a lifetime trying to make sense of it, learning to live with it, discovering new aspects of what it means to spend a little time (whether it's five years or 95 years) doing this thing called "living". A child's death propels you on the journey of a lifetime. You find yourself, against your will, on a path you never knew existed. You make your way in darkness and, somehow, as if by magic, you slowly make your way forward. Dare I believe that Sascha's little hand is pulling me along? Sometimes I can almost hear him whispering in my ear, "Come on Mama, I know you can do this. Yes you can. I love you and I want you to find happiness again. You can do this. You can do it for me. Come on Mama... I want you to be happy." He has the sweetest voice. I listen and I take small gentle steps forward. It takes a looooooong time to learn to trust one's feet again.

You start with teeny-tiny baby steps, just as your child did when he first learned to walk. You learn to wake up again, you learn to buy groceries and run errands, you learn to interact with other people and, one miraculous day, you even learn to laugh again. Then, the fact that you have smiled or laughed horrifies you and you have to take two steps back again before you can proceed again. The path of healing is long and winding and one stumbles most of the way.

When you lose a child, you start from the beginning. Everything you thought was true, you discover is questionable. Things you valued, you realise are meaningless. Things you took for granted you realise are miraculous gifts for which you must be profoundly grateful. You see, for the first time, the shallowness of things. Likewise, you see beauty in mundane things you would have neglected in the past. What is real and what is not are concepts you must reconsider. Your life has been shattered and your spirit annihilated. But, cruelly, your heart still beats. You have no choice but to rise from the ashes. People will call you brave, but the truth is you had no other choice. And since you're forced to stick around, you discover that your perception changes, that your life changes, that you change. In this, you have no choice. It is, if nothing else, a humbling experience.

farewell, my child

I know Sascha loved me and I know he would never have done anything to hurt me. And so, I believe, he must have broken me for a reason. I will spend a lifetime trying to find that reason. I work hard to find positive outcomes. I experience new loves, new motivations, new ways of being; I try to make my life a life worth living. He would have wanted that. He has filled my life with great love and great sorrow and, therefore, also great meaning. The music of my life continues, but the score is immensely richer for having loved and lost a little angel of my heart.

The Saddest Sound

The saddest sound
I ever heard
was the silence
that met my ear
when I rested it
softly on
your sweet chest.

– Kendra Frazier



Shai-Ann

Shai-Ann Kaela Tam Rong En
15 – 22 February 2004

Joe and Stefanie were already loving parents to 18-month-old Nathan when they conceived Shai-Ann. Their joy turned to dismay and fear when they were told at 20 weeks that she suffered from a rare but very serious heart condition (HLHS) and were advised to consider terminating the pregnancy. After much soul searching, they decided to continue to nurture Shai-Ann in utero and confront her fate, whatever that might be. Baby Shai-Ann fought hard to steal more time with her parents but only lived for one week.

Written by Isabelle Lim and Sonya Szpojnarowicz, from an interview with Joe and Stefanie, Shai-Ann's parents

At an early scan of their pregnancy, Joe and Stef were told that NT (Nuchal Thickening) was beyond the normal range, which was indicative of a possible complication such as Down Syndrome. Although they were advised to go for an amniocentesis test they decided against it, feeling that they would not terminate the pregnancy anyway, and wanted to keep this baby even if she had Down Syndrome.

They knew something was *really* wrong at the 20-week scan, when the ultrasonographer's very serious and silent demeanour confirmed their worst fears. Their doctor explained that Shai-Ann had HLHS (Hypoplastic Left Heart Syndrome). This is a rare and lethal condition where the baby's left heart is not fully developed (the left ventricle is too small to pump blood to the body)—and so is therefore unable efficiently to pump oxygenated blood to the body's major organs, including the brain and limbs.

They were told that serious corrective surgery would have to be done immediately after delivery to give Shai-Ann any chance of life at all, but that chances of survival at this first-stage surgery were slim—and if they were lucky enough for it to work, she would need further complicated surgeries to be carried out during the first few years of her life.

That day was a whirlwind—they saw four or five advisors, including a medical counsellor and a professor, who drew diagrams of the heart to help explain what HLHS meant. Very little hope was given, and they agreed heavy heartedly to schedule an appointment to terminate the pregnancy—on the advice of the hospital where professionals seemed more inclined towards a “practical decision”.

The following time was a roller-coaster ride of emotions for Joe and Stef. Their parents were at first inclined towards ending the pregnancy, saying that the loss would be greater if they struggled on through the rest of the pregnancy and delivery only to lose their daughter then, or worrying about how difficult it would be if they had to see her strapped with tubes. Stef understood their concern, but explains, “as we gave it more thought and feeling, the answer became a little clearer. We wanted our baby and we wanted a chance at life for her. So we decided to name her ‘Shai-Ann Kaela Tam Rong En’ (Shai-Ann means ‘The Lord God Almighty’, Kaela means ‘Beloved’, the Chinese name Rong means ‘Glory’ and En means ‘Grace’). This was the nicest name we could think of for our little girl, so it was really a precious thing to give to a baby who was doomed not to live. I’d begun to feel her movements, which made the thought of an abortion even harder. We also decided that we wanted to put our faith in God for a miracle of healing—so we prayed that she would be healed despite having the heart condition during pregnancy. We hoped that perhaps at birth or in subsequent days after birth, she would get better and not need any surgery. Our parents, family, friends and church, although they had their own views, were very supportive of our decision, giving us moral, emotional and spiritual support whenever needed. They all knew it was a tough call and were understanding towards what we had to go through just in making a decision.”

Joe and Stef swung from confidence in their faith that somehow Shai-Ann would be healed, to despair over her uncertain fate. They tried to suppress their doubts and fears, holding onto their Christian faith in God’s purpose, believing that there had to be a greater reason why this had happened to them. But they also tried to prepare themselves to accept that Shai-Ann might not be healed and might not be meant to live. Stephanie says, “While we, being human, tend always to want reasons for everything, we had to learn that sometimes some things are just not meant to be understood, but to be accepted gracefully.”

Shai-Ann was born on the afternoon of 15th February 2004, and was immediately taken to the NICU for ventilatory support, tube feeding and sedation. Stef recounts, “We wept when we saw her. Her being born was a miracle in itself....She looked so perfect. And it was painful knowing that she wasn’t perfectly formed inside.”

Things seemed to be going well—on the 3rd day, the oxygen and sedative were

reduced and she seemed to be breathing quite well on her own. The following day she was taken off intensive care and moved to the Quiet Room at the Special Care Nursery. The next day, Friday, Joe and Stef were overjoyed to see their tiny daughter drink some milk from a bottle, although she panted a little, and to see her open her eyes and look at them. They began to hope for a miracle, and there was even talk of going home over the weekend.

But on Saturday morning everything started to go downhill. Shai-Ann's oxygen levels fell and she had to be sedated again. Family and friends came to the hospital to be with them all as everyone thought that this was "it". But her condition stabilised and she slept for most of the day. Joe and Stef couldn't bear to leave her and decided to spend the night at the hospital. She was panting breathlessly, and at about 4.00 in the morning the staff told them that Shai-Ann was unlikely to live until daybreak.

Shai-Ann died peacefully as her parents cradled her, kissed her, talked and sang to her. Stef says, "We were grateful that she had given us a 'warning'—her deteriorating condition on Saturday made us decide to stay overnight, which gave us the opportunity to be with her at 4.00 am when she was in distress. And we were grateful that we could be alone with her in the quiet of the night during her last hours. I had the chance to talk to her and share my dreams with her, to take time to kiss her goodbye and just hold her and touch her. I do think that she hung on to her life and fought for that one extra day of time, for us."

As Joe and Stef drove home that morning, Stef recounts, "I saw a sunrise that I will never forget. It was beautiful—the clouds, the skies. It gave me a sense of peace. For some reason, I saw the heaven that my little girl had gone to and I was happy for her. Happy and relieved that her pain and suffering was over. It was really a bittersweet moment. And I told my husband that we should take a morning drive on her death anniversary just to remember this peace."

Stef tells the story, "We missed her a lot and for a couple of weeks, I think I cried almost every day. I'd write letters to her telling her how I felt, or what her brother was up to, and even what I wish I could have done. It was especially difficult during my son's afternoon naptime, because the house would be so quiet and I could imagine that if Shai-Ann was home, she'd be crying for milk or something. Her cot was still not dismantled, the toys and little pillows—everything we'd prepared in faith that she would come home, was left untouched for a few weeks.

I would also drop by the shop in hospital mall where we bought the dress that she wore for her wake/funeral. I'd look for a dress of the same design just to remember how it looked on her and the feel of it. Maybe the sales staff think I'm loony as I do go there fairly often just to do that!

It helped that we agreed to talk openly about her and the loss, to share our feelings with each other, and never to condemn anything felt or said by each other, especially if one of us took longer to 'get over it'. It also helped that we gave each other the space to

grieve on our own as well. Crying openly was NEVER taboo. Just lots of hugs and understanding. The key thing was never to bottle up or hide any feelings about our loss.

Our journey with Shai-Ann brought us closer as a couple. Her life brought healing to some parts of our marriage, which I thought would take a miracle to mend. But they did. I do regret that it took our baby's life to mend her parents' relationship. I am eternally grateful to her.

And of course, it was a joy to know we were pregnant again. A church friend was concerned that we would see this third child as a replacement of Shai-Ann, but it is never so. In our hearts, we are parents of three children (how can I go through three full-term pregnancies and not remember how many!) even though (for convenience) sometimes, we just say that we have two. And we can't wait for the day we can tell Shai-Ann's story to her brothers, so that they can receive her into the family as we did, and be proud of her spirit and her life as well.

Joe and I talk a lot about what Shai-Ann might be like if she had lived, whether she'd be like her brothers or not, how old she would be today, what life would be like if she had survived etc. We do talk about that one week as well, but not really in detail. There is a song by 3 Doors Down ('Here Without You') that Joe reserves specially for her, and I tear up when I hear Sarah McLachlan's 'Answer'. (I heard this on CD one morning on our way to visit Shai-Ann in SCN. It couldn't have been a more painful moment in the car.) We mention her quite a bit in our conversations with other people (those who knew and went through the time with us). My Dad recently said she was the prettiest baby out of the three (I thought, 'Of course lah, she's a girl!') And because her Birthday (15th February) is almost exactly one month after my 3rd child's Birthday (14th January), we had a time of remembrance with family and close friends, together with Jed's first-month celebration. We plan to tell the boys about their sister when they are old enough to understand, and to place her urn at a niche as a family occasion. She is very much part of the family and we keep her very much alive in memory.

Our pastor asked if we have 'let her go'—yes, we have definitely let her go. But it doesn't change the fact that she is our child and we're her parents. It's just like having a daughter marry and move abroad. You let her go but you don't love her any less at all. And our way of loving her is to share her life and her courage with others, because we're so proud of her."



Victoria

Victoria Jane Baxter
28 July 2000

Vanessa and Tim are Australian expatriates who have lived in Singapore for 18 months. Vanessa shares the loss of her first child.

Written by Vanessa Baxter, Victoria's mother

Our first pregnancy was complicated from the beginning. I suffered morning sickness all day long and felt exhausted and frustrated rather than elated and blooming. Yet I typified any first time mother-to-be. I bought a journal to fill in, pampered myself with oils and massage, listened to relaxing prenatal music and dreamed of finally having a baby in my arms. When the doctors expressed concern following a scan at 13 weeks we were numb. These were early days though and our naivety and innate desire to err on the positive provided us with strength to continue. We struggled through the weeks with conflicting test results and scans, our little baby battling to grow healthily. By 28 weeks it was evident that her brain was malformed, her limbs were growing at different rates and my placenta was weak. All advice leant to allowing her to rest in peace and so with prayer and heartfelt guidance we made the painful decision to guide our first baby straight into the arms of our Father.

Following is the poem I wrote in the face of this terrible loss, the mystery of which overwhelmed us at the time.

28th July 2000—To Victoria Jane:

Our dream was to have you
Share in our life
To fill all our days
With laughter and light

Our time together
Our memories are few
But our love for each other
Reflects our love for you

Your journey seemed
Altogether too brief
And right now
Our lives seem consumed with our grief

But God had you chosen
Right from the start
And has brought you
To heaven and into His heart

As parents your memory
Will make our lives whole
And together, forever
We will pray for your soul



The Human Comedy (adapted excerpt)

I'm not going to try to comfort you,
I know I couldn't.
But try to remember that the
goodness of a child can never die.
You will continue to experience
this goodness many times.
You will experience it in the streets.
You will experience it in the houses,
in all the places of the town.
It will be in the vineyards and the orchards,
in the rivers and the clouds, in all the things that make this
a world for us to live in.
You will experience this goodness
in all things that are here out of love,
and for love—all the things that are abundant,
all the things that grow.
A child may leave—or be taken away—
but the goodness of a child stays.
It stays forever.
love is immortal and makes all things immortal.

– William Saroyan

COPING WITH LOSS

PARENTS SHARE THEIR EXPERIENCES

The awful reality of losing a beloved child is something we face with extreme difficulty. But it IS possible to cope with it and to keep on living, slowly learning to accept it and eventually finding some kind of personal peace or closure. It is very important to remember to take one day at a time. From our various experiences we have gathered together some thoughts on things we found helpful to keep us going—or things we wish we'd known at the time:

He will always be your child

You will never stop loving your child, nor being his parent, just because he is no longer with you—this brings both pain and comfort. It means that you live with the pain of your child's loss forever, and that your heart will always yearn for him to come back. But it also means that you have a very special bond with your child that stays with you always. No one can ever take away your memories, your dreams and your love for your child.

No “right” or “wrong” way to grieve

Everyone will grieve in his or her own individual way—it is important to remember that there is no “right” or “wrong” way to grieve. There are “patterns” of grief, often referred to as “stages” (we will not go into these in detail as there are so many books that do this very well already), but many grieving parents will not go through these “stages” in the typical order described in many grief books. Max's mother Sonya says, “I know that I often felt that I was going through many ‘stages’ all at once, and that one day I seemed to be in one stage, and another day it seemed that I had gone back to what was supposed to

farewell, my child

be a much earlier stage. It was frightening to feel so lost and out of control. I could feel brave and strong one minute, looking to the outside world as if I was coping well—and then suddenly find myself in floods of tears for no clearly apparent reason. Likewise, there were times when I wanted so much to cry openly, when a kind friend was being supportive and I wanted to open up about how utterly awful I felt—but I couldn't take off my brave face.”

It is also important to stress that you have to grieve as YOU feel you need to—no matter if others might expect something different or might consider you selfish for not following their expectations or customs. Daniel's mother Stefanie says, “Often the bereaved are expected to follow with tradition and do certain ‘stuff’, but if that is not right for you, do what is, and don't feel the need to follow on as tradition dictates. Others CAN NOT understand, so don't worry about fitting their agenda. It is hard to defy common practice and family rituals but the family has likely not experienced this loss before. Do things in your time and do what you see fit.”

Allow yourself time

One thing that is very important is to be patient with yourself and give yourself time to grieve. It can be very damaging to feel that you “ought” to have got over it and to have “moved on”. Experts agree that it takes many years for a bereaved parent to work through the grief process. So much will depend on the particular circumstances and so many things can complicate the process and serve to make it harder and longer. Added complications and sources of pain include babies that are stillborn, where the mother has had to give birth to death; children who have died particularly painful or horrific deaths; death of an only child or much longed for and difficult to conceive child; and parents who suffer guilt over their child's death—maybe they felt they failed to spot symptoms, failed to protect their child, should never have let them go out on their own. . . .

Go with the flow

Grief is a frightening new universe. You might be used to feeling “in control”, feeling confident in facing the world, proud and strong and invincible—and now suddenly you might feel totally lost, powerless and terrified. Try not to worry about feeling out of control—allow yourself to go with the flow. Alexandra's mother Marina tells of how she hid away under the covers in her darkened room, taking a long time to emerge very slowly into the outside world. Max's mother Sonya recalls how she took to wearing glasses instead of her usual contact lenses—so that she could take them off and “zone out” the world, sending everything into soft focus. She says, “I felt as if I wanted to hide away in a dark hole and not look anybody in the eyes ever again.” All this is OK. Grief for a lost child is agony—there is nothing wrong with howling, crying hysterically, hiding away—do what you have to do to get through each moment.

The only way is through it

There are no short cuts to grieving—it is a natural, unavoidable process, and part of life. Taking medication may be a temporary fix but it will not solve the problem and one day you will have to face life without that help. We have to face up to the reality of our child's death, and to go through the pain of grieving their loss, if we are ever to find any kind of resolution and be able to move on with our lives with any kind of meaning. Facing up to the reality means things like seeing and touching your child's body, putting their possessions away, and talking openly about your child and about how you feel. In Jerry Sittser's book, *Grace Disguised*, the author relates a dream he had where the sun was setting and night was coming and he was running towards the sun trying to outrun the darkness. He ran, terrified, realising he couldn't outrun the darkness. Then he realised that the only way to get past the darkness was to turn around and run directly into it—that through the darkness was the fastest way back to the sunlight.

Pace yourself

While you have to go through it, you don't have to deal with it all at once. It is equally important to "pace" yourself over your loss. If you don't feel you are strong yet to pack away his things, or look at his video, you don't need to do it *now*. It took Ning's mother Val two years before she could watch a music video of Ning. And some parents prefer to leave their child's room intact instead of putting away their things. Remember that you can revisit these issues when you feel stronger, even if it means taking years to mull over them. It's OK. But you will need to go through it at your own pace.

Be patient and kind, and nurture yourself

Whatever the circumstances, you must be patient and kind with yourself—and with your partner. The death of a child can put unbearable stress on the relationship of the parents, as you have both suffered an unbearable loss and so in many ways are both unable to help each other, whilst both needing love and support more than ever before. Try to nurture yourselves, give yourselves little treats, no matter how small—anything to make life a little easier or more comfortable. Take care of yourself physically—try to eat properly, to rest and sleep. Many of us have found it very difficult to sleep for a long time after our child's death—Max's parents Sonya and Chris sought the help of their GP who recommended a mild antihistamine tablet (as it is non addictive and is out of the body's system after 12 hours so doesn't leave you feeling groggy the next day) and say it really helped.

Divert your energy

You may suddenly feel that although you have a lot of free time on your hands, your life no longer has meaning or purpose. Ning's mother Val is not alone in saying that she

would often just stay in bed and spend her energy crying. With nothing to do, it can be all too easy to fall into what she calls a “spiral of sorrow”, leaving you exhausted from crying and heartache. Falling into a lethargy of despair could be damaging to you physically as well as psychologically, if left unchecked. It may then be a good idea to divert this energy elsewhere. Many of the parents in our network have found great comfort from volunteering at places like the Assisi Home & Hospice (a day centre at Mount Alvernia Hospital for children with cancer) or the Rainbow Centre (a day centre for children with special needs) or helping to paint rooms at the KK Hospital NICU. Help your mother or the old lady next door by doing their marketing. Go window-shopping or to the museum or (if you feel up to it) to your child’s favourite parks. If you can muster the energy, it can also be very beneficial to be physically active—many parents have found running, or long early morning walks, therapeutic—this may have the added benefit of reducing insomnia. Many people feel that by pouring their energy into physical activity, particularly if it helps others, they are helping to expel their own emotional pain.

Memorials—remembering with love

Memorials provide an invaluable way of staying connected with your child, of acknowledging them and remembering them with love. Memorials can be private or public, and have many forms of expression. Max’s family have a bench at the Zoo, at one of his favourite exhibits (the chimpanzees) with a small plaque with his photo, and their friends at home in the UK planted a tree for him. Friends of Grace’s parents have named a star after her. Grace’s father made a compact disc with special music and photos. Edward’s parents keep his footprints, and planted a fragrant white flowering bush in the front of their house. Alexandra’s uncle placed a memorial plaque with her name in a new church in London, and her aunt planted a tree for her in Scotland. Friends of Alexandra’s parents raised money for a new incubator at the NICU where she died. Another friend has written a cookery book with her daughter’s favourite recipes. Both Jordan’s parents and Jakob’s parents have set up websites with their children’s stories and pictures. Sascha’s parents make a donation to a different charity every year on his birthday to honour his life and the goodness he would have brought. Others have established special scholarships, commissioned statues, donated a special item (like a stained glass window to a church, or a work of art to a school, or a special book to a library). We all keep favourite framed photos.

Friends can also help with memorials. A few months after Alistair died his tennis group organised a special tournament in his honour, and made a beautifully engraved “Alistair Cup” as the trophy. This also allowed all his friends to join in and remember him together.

Talk about him, tell your story

Most of us will find it immensely difficult to talk about our child's death, particularly in the early weeks and months. But it can be very therapeutic. Ning's mother Val says, "It took me a while, but I now believe that telling my story about Ning's death helped me manage the reality of my loss. The repetition at first left me miserable, but the more I told my story, the stronger I felt. I am still heartbroken every time I relate it, but not in despair. And I would mention her name if it comes up which may sometimes surprise people. I remember replying to a question "I have three kids—two boys and an angel". I felt good that I did not deny having three children." Many people, friends and acquaintances and maybe even relatives, might be afraid that if they mention your child's name that it will cause you even more pain. It can help you as well as others to let those around you know that it is OK to speak of your child—that remembering your child is painful, but not as painful as NOT remembering your child. Others will be put at ease by your instruction, because they also do not know what to do or say to help you.

Help siblings to remember without fear

One of the most difficult parts of dealing with your grief for your lost child is to try to explain things to surviving siblings, and to help them to understand what death means whilst not frightening them. Ryan's mother Jeanne talks of how difficult it has been to try to protect his 8½-year-old brother Russell from her own pain, putting on a "brave face" when all she wanted to do was collapse in tears. She and her husband Nicholas worry that Russell has had to mature early. Another bereaved mother, Gracie, talks of how she and her husband involve their older son Marco in their weekly ritual of tending Luca's grave, and how they make it a family outing and visit nearby farms. Jordan's mother Adriana always talks to her two-year-old daughter Charlotte about her special baby brother—every night before she goes to sleep Charlotte goes to look at the stars and says she's saying "Good Night" to Jordan. And five years after his death, Sascha is still very much a present member of the family. As the only member "in spirit" he has a very special place in everyone's heart.

Rebecca and Fabian were told at four months of pregnancy that their baby son faced severe developmental problems and that he would not live long—so they had a long time to prepare their two-year-old daughter Ashley. They talked to her about it, and explained to her that her baby brother would not look "normal" (he had a very small head). Baby Lyndon lived for nine months, and Ashley loved him very much. Even though she had been warned that he wouldn't stay forever, she was shocked and saddened when he died, and screamed, "No! I want God to give him back to me." She missed him so much from her daily life, and was very unhappy. A child psychologist who was an acquaintance suggested they let her write a letter to Lyndon—so with the help of her

mother she decorated a card with hearts and stickers and wrote that she loved and missed him, and drew a picture of them together under a rainbow. They put it in an envelope, addressed it “To Lyndon, Heaven” and posted it in the postbox. This has given Ashley some peace, and helped her to feel a connection to the baby brother who was such an important part of her life and whom she misses so much.

Even with younger children, it can be a challenge—when Max died, his brother Lukas was only four months old, so his mother didn’t have to worry in the same way as Jeanne about putting on a brave face for him, and could cry openly. But she recounts how he quite obviously picked up on her sorrow and on the changed world that he lived in: “I will never forget the look of delight and recognition on his face the day we saw our friends’ son (who looked a lot like Max and was around his age) about a month after Max’s death.” Now, nearly three years on, she says that Max is an important part of Lukas’s life: “We talk about him, look at his pictures and videos of him. Lukas doesn’t yet have a mature understanding of what death means, but he does know that he has a brother who is dead, whom we still love and miss, who can’t ever come back, and that we’re sad about that. I believe that it’s very important to talk openly about Max to Lukas and to my younger children—I want them to grow up with a slowly deepening understanding, and never to remember the moment they were first told about their dead brother.”

Siblings keep the continuity

You may have lost your only child now without knowing if you will have another. Or you may already have other children. Whatever the circumstances, it may be helpful to allow some continuity to help in your grief process. Keep some of his things with you for his siblings (present and future). You would be amazed how a simple object can connect you to your lost child. Ning’s parents had no other child when she died, but they kept many of her favourite toys and clothes with the hope of having other children in the future—and today her brothers wear her tees, play with her cooking sets, tent, soft toys and other things. Her parents feel that this underscores the little life she had with them, short as it may have been. Sascha’s mother kept a small trunk of his special toys, shoes, clothes, books and artwork, as well as his birth and death announcements. She plans that her other children will in time be allowed to choose what they would like to keep themselves from his trunk.

But remember that you must pace yourself and go slow if you need to—Max’s mother Sonya says, “I know that in the first months after Max’s death I could not cope with dressing Lukas in Max’s clothes or having Max’s toys out to play with, and in fact I found it far easier to make things as different as possible—but in time, all the boxes of Max’s clothes and toys have come out, and his younger brothers all get to share his things, and now I love it—it helps me to feel that Max is part of the family. I still keep some special things away though, just for me to remember.”

You are not alone—journey with your spouse

Remember that you have your spouse to journey with. He or she feels the loss as intensely and feels the heartache as deeply. You may need time on your own, but allow time together too. Both Alexandra's parents and Ning's parents found that going away on a trip together, away from "normal life" and the distractions of work and family/friends, really helped them to understand each other's feelings, regrets, hopes and fears. Ning's mother Val says, "We talked and discussed each other's needs and raised the difficult question of whether we would have another child. We found it important to plan our days and weeks together, to be accommodating with each other, and to draw strength from each other. One thing I am always grateful to my husband for was his tact in telling me when I should stop wallowing in my grief. "OK, enough for the day" he would say jokingly, or, "Ning's watching...she wouldn't want to see you like this." We would then go for a walk, and it made us both feel better."

Use resources

There are many excellent books on grief: guidebooks written by counsellors and psychiatrists as well as personal accounts by bereaved parents (see Appendix 2 for recommended readings). Max's mother Sonya says, "When we could finally force ourselves to venture out into the world we went to scour bookshops for books that might help. I found reading these books hugely therapeutic—I could identify with so much and realised that I was not alone in this frightening new world, that there were many others who had walked this rocky path before and survived, who had felt all the heart wrenching things that I was feeling. In the many, many long lonely hours late at night when we couldn't sleep, I would read chapter after chapter of these books aloud to my husband."

We have also found support through the many excellent websites on the internet, particularly reading other bereaved parents' accounts of their own experiences (see Appendix 3 for a select list). Some of us have made good friends through these sites and their organisations. Ning's mother Val talks of the comfort they found from realising that other people had "survived" their losses and were coping in various ways: "These bereaved parents bear testimony to the saying "life goes on", and that it was possible to find new routines, develop new interests, engage in new activities, and be happy again eventually. It seemed almost impossible to imagine this in the initial weeks/months/years of our loss. But each of us have our silver lining somewhere and we mustn't lose hope."

Religion/spirituality

Parents who have a religious faith have often found that it has given them enormous strength—and some say that they do not think they could have survived without it. Others have turned away from their faith, feeling "let down" by God. Some have turned away in anger only to turn back to find comfort once again. Some parents have felt that

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their faith in a loving God and in an afterlife gives them hope—most importantly, hope that their child is in a happy place, and that they will be reunited once again after their own death. Religious rituals have been enormously comforting to some parents (see what Annika’s parents wrote about their Hindu beliefs). And parents who might not have any religious faith have found comfort in spirituality, believing that their child’s soul survives and that there is a deeper meaning behind their child’s death.

Tiny steps

So give yourself time, allow yourself to “go with the flow”, and don’t set yourself great expectations of how you “ought” to be facing the world. Take tiny steps as you move through this unfamiliar new world, congratulating yourself (and your partner) for just getting out of bed and getting through another day, and not giving up and hiding in a darkened room.

You will never “get over it”

Remember, you never “get over” this loss. You only learn, ever so slowly, to live with it. Many other people will be expecting you to move forward at an astonishing rate of recovery. Be kind, gentle and patient with yourself while your broken heart tries to learn to accept the unacceptable—it is by nature a very slow process, full of setbacks and challenges.

One Loving Act

If I can stop one heart from breaking,
I shall not live in vain;
If I can ease one life the aching
Or cool one pain,
Or help one fainting robin
Unto his nest again,
I shall not live in vain.

– Emily Dickinson

HELPING BEREAVED PARENTS

WHAT YOU CAN DO TO LEND SUPPORT

It is very difficult to see someone you love in extreme pain—even more so when you can in no way “fix” the problem and the only thing you can do is just hang in there for as long as it takes (which is a very long time), patiently listening to the same things over and over again, allowing the grieving person to cry, get angry, stay silent, feel self pity or even express suicidal emotions. In the face of such overwhelming pain and sorrow, friends and family often don’t know what to do or say, afraid of saying the “wrong” thing, and are likely to feel quite powerless as a source of support.

It must be particularly difficult if you too are grieving—if you have lost a grandchild, niece, or godchild.

Be patient

I think that one of the most important things is to be patient—allow the grieving parent as much time as they need to work through the grief process. No one can say how long it “should” take—no one should ever say to a grieving parent that “It is time to get over it” or “You must pull yourself together now”.

Realise that you can’t fix it

Nothing can bring back the dead child—so nothing can “fix” the situation. Everyone feels powerless in the face of the death of a child. You have to accept that you ARE powerless—that your role is not to come up with some kind of solution but rather just to be there. Being a support through the pain means being both witness and validator. Do not be afraid to show a bereaved parent that the loss has affected you deeply as well—parents appreciate knowing that others are saddened by the death of their beloved child. It helps parents to know that others know they have suffered a tragic, unbearable loss that can neither be replaced nor repaired.

Don't try to minimise the loss

In a well meant attempt to make a bereaved parent feel better, it can be all too easy to say something that would appear to trivialise the loss, which can really rub salt into a parent's wounds when they feel that they are facing the most enormous, overwhelming tragedy. Many of us in our group have been stung with, "Never mind, you can always have another baby". Please never say this to a bereaved parent, it really hurts! A child that has died can never be replaced like some commodity; and for all you know the couple may not be able to conceive again; or the baby who died may have been born only after a long struggle to conceive. So, whatever you say, please appreciate and acknowledge the enormity of the bereaved parent's loss and grief—don't refer to such loss as a "mishap" as one unthinking doctor did to Grace's mother Trish. And please don't ever say to a bereaved parent, as someone told Sascha's mother Kendra, "I know just how you feel, my pet died last year."

Acknowledge the child—always

The dead child will always be an important part of his parents' lives. Friends may forget, may in time adjust to seeing the parents without that child, and it might seem easier just to "move on" and see the dead child as a past chapter. But for the parents he will always be their child, and they will appreciate anyone remembering that child, acknowledging his life, talking about him as a person, using the child's name without fear or discomfort. This reaffirms for them the fact that the child lived and was loved dearly by those around him.

Active support in early days

In the early days after a child's death there are many practical things that loving friends and family can do to help. The parents may well be so dazed and in such a state of shock that they are unable to perform even the most mundane tasks. Being there to make cups of tea, provide food, clean up, help with routine household chores—these can all be a great help. Mothers from the St. George's playgroups organised a rota and delivered cooked meals to Max's family for a while, thoughtfully leaving them anonymously and discreetly so that they didn't feel obliged to talk to anyone or have their privacy invaded. Max's grandparents took on the horrendous job of sorting through his clothes and toys, cleaning, folding, sorting and packing everything. And his parents' two sets of closest friends filtered out the rest of the world for them so that they didn't have to face anyone—ensuring that the news was told to everyone who needed to know, helping with funeral arrangements and administrative necessities.

Continued support—hang in there

Even harder than being there in those whirlwind early days is to stay the course and continue to be there as a support to the bereaved parents. Many parents recount how it all seems to get even harder after the initial flurry of activity, when the funeral is over and there is nothing more to be done. When friends have gone back to their normal lives and the house is quiet again, the hard job of learning to cope with a shattered life and overwhelming grief only just begins. Alexandra's mother Marina says, "The friends that made a difference to me (a BIG difference) were those few who stayed the course and persisted and persisted with me. They would come and see me all the time, even in hospital, cook us dinner weeks and weeks after Alex's death and never behave as if things were all back to normal". Don't abandon a grieving parent—hang in there with them. Ning's mother Val says, "After the horror of the first few weeks, check in on the bereaved couple, and perhaps create occasions for them to just hang out with you and your family. It is always heartwarming when friends offer time to spend with you. Some bereaved couples appreciate having children around them, little friends of their lost child, although not everyone can deal with it in the early days. Use your intuition to decide how the couple feels." Friends of Alistair's parents continued to ask them to join in the social tennis at their condo—and even if they didn't always feel like it, they appreciated the gesture. They also appreciated friends inviting them for quiet dinners at their houses and not expecting them to talk much or stay long—but just continuing to include them and care about them. Three months after Sascha died, a close friend of the family came from far away to stay for a while. She helped to pack his clothes away and spend time with the other children. But she didn't just come that one time, she continued to write, express her concern for years, remembering death and birth anniversaries, and visiting whenever possible. This is real friendship and it makes a big difference.

Don't be afraid of their tears

Often friends will feel that they are treading on eggshells, trying not to say the "wrong" thing that might make the grieving parent start to cry. But bereaved parents need friends who can cope with their sorrow and not be afraid of their tears—it can be such a support to be with someone who genuinely cares about you and with whom you feel completely safe to open up and cry. The grief is not going to go away—crying is not going to make it worse. Showing your own tears is a way of showing solidarity and, in a strange way, it soothes the bereaved parent to know that others are also deeply touched by their child's death.

Remember birthdays/anniversaries

Friends would normally remember the birthday of a child when he is alive—so please try to do the same after the child has died. It can be a very touching gesture to the parent that their lost child still “counts” if a friend remembers his birthday, death anniversary or other special date. Even when two, three, four or many more years have passed, it is still comforting to know that others remember the day your world changed forever. This is also an acknowledgement of the fact that even years later, you will still be deeply affected by the fact of your child’s birth and death.

Alistair’s school has not forgotten him: after he died they set up an “Alistair Corner” where children at the school could write anything they wanted in a special big book. With sensitivity, the school invited Anne and Helmut in to collect the book, and the things from Alistair’s locker, during the school holidays when the place was quieter. And a year after his death, the school arranged a tree-planting ceremony in his honour.

What Do You Say?

What do you say when a baby dies and someone says...

“At least you didn’t bring it home”.

What do you say when a baby is stillborn and someone says...

“At least it never lived.”

What do you say when a mother of three says...

“Think of all the time you’ll have.”

What do you say when so many say...

“You can always have another...”

“At least you never knew it...”

“You have your whole life ahead of you...”

“You have an angel in heaven...”

What do you say when someone says...nothing?

What do you say when someone says...

“I’m sorry”.

You say, with grateful tears and a warm embrace,

“Thank you!”

– Kathy Mayo

(written for The Child Bereavement Trust)

REFLECTIONS FROM A NURSE

Rahimah Bujal

*Nurse Coordinator, Home Care and Bereavement Support
Neonatology Department, KK Women's and Children's Hospital*

As nurses, we have been rigorously trained and professionally prepared to face every thing from the most minor of grazes and skinned knees to the most horrendous medical woes of the human body. It is bad enough to see an adult suffer—and it is even worse when the suffering is borne by children. But there is nothing quite like seeing newborns and young babies hooked up to machines. At first glance, one wouldn't even be able to see the baby at all, with a massive network of tubes and wires covering a small, frail body.

My years as a nurse have trained me to accept this as part and parcel of life and death. We learn how to keep up a professional image that might seem cold and clinical to some—but behind this façade my nursing peers and I have cried silently for the babies and their agonised parents. This is the harsh reality of Neonatal Intensive Care Units (NICU) and special care nurseries for sick babies.

I have journeyed with many parents, through providing and assisting with “Home Care” (helping and teaching parents to care for their special needs babies) to helping with providing funeral arrangements for lifeless babies of distraught parents. Every case is different, and when any of these babies and children die it is always heartbreaking and emotionally draining.

One of my most memorable cases dealt with an “anencephalic” baby—meaning she had no scalp, leaving brain matter exposed. The youngest of four siblings, this baby was a much wanted baby whose parents couldn't bear to terminate her life even though antenatal checks had already shown the anencephalic condition. When she was born, her parents made sure that her siblings were there to welcome her into their warm family fold, anencephaly or not.

She went home with her parents and even managed to spend a good fortnight with her family. Then came her eldest brother's birthday and she was unwell and was gasping

for air early that morning. I was on duty at the hospital and could only monitor the situation via telephone. I managed to calm her Mummy and advised her to say her prayers to help her baby daughter to go in peace. When I finished work later that evening, I hurried over to their home to find a very visibly distressed mother who was on a verge of a breakdown as her daughter was gasping for air and couldn't just slip away peacefully. The Mummy was so upset at seeing the pain that her baby was in, but everything was being made even worse by insensitive family relatives who were making unwittingly hurtful remarks.

I asked the Mummy for permission to hold the little infant in my arms. As she nestled with difficulty all the while trying to breathe, I whispered gently to this little baby of the warm and fuzzy family love that enveloped her. I told her how her Mummy was willing to let her go but that she would never be forgotten. Just as I whispered my last word, the baby girl took her last breath and left.

My story would have ended there as I left the household but I was disturbed and shaken. As I was taking my leave, the Mummy thanked me and insisted that her baby had been waiting for me to say goodbye. I questioned my self-worth and capabilities. I was a nurse, how could I have been a messenger of death? Was my purpose in life to help send off the dying to the nether world? Then came the answers almost immediately—in showers of blessings, literally. The rain came pelting down in buckets and I had never in my life felt so overwhelmed by emotion.

Those showers of blessings made me realise that although our jobs are emotionally stressful, my peers and I have grown and learnt much from our experiences. We have come to appreciate the different kinds of love that parents have for their sick children; and how far they are willing to go, the things they are willing to do just to have those precious moments with their babies, no matter how brief.

Some of my days at work are filled with highs—seeing babies recover well enough finally to go home. But some days are filled with the lows of having to see babies die. But through each day of highs and lows, no matter how clinical we appear to be, we want all parents to know that we—the nurses, the doctors and other healthcare professionals—are on your side, no matter the circumstances. For in our eyes, you, the parents and your babies are the reason why we love what we do.

What Will I Say?

I won't say I know how you feel—because I don't.

I've lost parents, grandparents, aunts and uncles, friends. But I've never lost a child. I came close, once. I had a miscarriage, but it's not the same. So how can I say I know how you feel?

I won't say you'll get over it—because you won't.

Life will have to go on. The washing, the ironing, the cooking, the cleaning, the common round. These chores will take your mind off your loved one, but the hurt will still be there. A small corner of your heart will grieve forever. Life carries on, but it will never be quite the same.

I won't say "Never mind, your other children will be a comfort to you—because they may not be."

Many mothers I've talked to say that they easily lose their temper with their remaining children. Some even feel resentful that they're alive and healthy, when the other child is not. Children can be cruel too. They may not understand death.

I won't say "Never mind, you're young enough to have another baby"—because that won't help.

A new baby cannot replace the one you've lost. A new baby will fill your hours, keep you busy, and give you sleepless nights. But it will not be the one you've lost. And you mustn't try to pretend it will.

You may hear all these and other platitudes from your friends and relatives. They think they are helping. They don't know what else to say. You will find out who are your true friends at this time. Many will avoid you because they can't face you. They'll cross the road to avoid talking to you. Others will make the effort to talk to you. They'll talk about the weather, the holidays, the school concert, but never about your child—never about you and how you are coping.

So what will I say?

I will say I'm here. I care. Any time. Anywhere.

I'll cry with you if need be.
I'll talk about your loved one.
I won't mind how long you grieve.
I won't tell you to pull yourself together.
I'll sit with you during birthdays and anniversaries.

No, I don't know how you feel—but with sharing perhaps I will learn a little of what you are going through. And perhaps you will feel comfortable with me, and find your burden has eased.

Try me.

– Linda Sawley
(UK Nursing Times, 1988)

Ode (excerpt)

It is not growing like a tree
In bulk, doth make man better be;
Or standing long an oak, three hundred year,
To fall a log at last, dry, bald, and sere:
A lily of the day
Is fairer far in May,
Although it fall and die that night;
It was the plant and flower of light.
In small proportions we just beauties see;
And in short measures, life may perfect be.

– Ben Jonson

ADVICE FROM A MEDICAL SOCIAL WORKER

Jeanne Leo
Medical Social Worker

The death of a child appears to defy all laws of nature. It just does not feel right for a child to die before his or her parents do. There is even a Chinese saying about how the white-haired sending away the black-haired is against the natural laws of order. When a child dies, all the dreams and hopes the parents have for him or her die along with the child. There could also be a sense of helplessness and guilt. Feeling helpless as one is unable to protect the child from harm or illness. Feeling guilty as one is unable to fulfill the responsibilities and duties of parenthood, which are to protect, love and care.

It does not matter whether the child is an infant, or even a little heartbeat on the ultrasound. Any parent would feel the anguish and despair. No one can really feel the extremes of emotions except you. This emotional coaster-ride could continue for a long period of time.

How then can you brave through this testing period of your life? We've listed some ways in which you can try to cope during this difficult period.

Rituals are meaningful rites which you and your family can do to close this painful chapter of your lives. Rituals can also help the other members of the family to come together to mourn and grieve.

Taking care of yourself is also an important element in the journey of healing from the loss of a loved one.

For a period after the loss of your child, it would appear that there is no meaning in life. At such times, having small goals would be helpful. Planning something would give you something to look forward to. Like going for a jog with your best friend tomorrow, watching a movie this weekend, a short trip next month. Such little plans would help you through the immediate future. Take one day at a time.

There are many little tasks which you can do to help yourself along the journey of recovery.

Give yourself some time and be kind to yourself. Eat regular meals. Get regular physical exercise. Have adequate rest.

Keep a journal—some people find it helpful to write down their thoughts and feelings. This expression of our deepest thoughts and emotions allows us to ventilate without the fear of making people around us feel uneasy.

Resume routine activities as this help you to minimise changes and stress.

Start with an activity which you find relaxing—this can help in the initial phase to get back to a normal cycle, and it can provide some stability and familiarity. You can try gardening if you find solace in it.

Reading books on grief and loss—for some, reading about someone else's experiences with loss can be very helpful. For others, learning about the normal responses to grief helps in their coping.

Talk about the person who died, if you want to—even though it may be painful, talking about particular memories can be healing.

Travelling during the festive holidays may also be helpful. It is also important to reminisce. Being reminded of the past can be essential to the process of coming to grips with a loss.

Postpone major life changes. Try to hold off on making any major changes, such as moving, changing jobs or having another child. You should give yourself time to adjust to your loss.

Be patient. It can take months or even years to absorb a major loss and accept your changed life.

Seek outside help when necessary. If your grief seems like it is too much to bear, seek professional assistance to help work through your grief. It's a sign of strength, not weakness, to seek help.

If helpful, go to a support group—many people find groups to be a helpful place to share about their grief. In such groups, they may experience the feeling of universality. This helps to affirm that you are not alone in your journey of grief. CBS offers regular support groups for all bereaved parents, and some hospitals have their own support groups.

This list is not exhaustive, for you may have other ways of taking good care of yourself. It is important to know that it is all right to feel sadness, pain, anger and loss. This spectrum of emotions would ebb and flow as the days pass.

Remember, you are not alone.

BEREAVEMENT SUPPORT SERVICES AT KK HOSPITAL

Department of Neonatology
KK Women's and Children's Hospital

Bereavement support services at the Department of Neonatology was introduced to support parents experiencing a terminally sick, dying infant or death of their infant at the Neonatal Intensive Care Unit / Special Care Nursery. The services offered to parents aim to meet individual parents' needs and to assist them through the grieving process.

Quiet room

This special room is located at the Special Care Nursery and was established to accommodate parents and immediate family members, allowing them to be with their baby for as long as they wish. The room is completely away from the general patient care area and therefore provides adequate privacy for parents who may also choose to room-in during the night. Having this special room allows grieving to take place as a family. Immediate family members as well as close friends are encouraged to be with parents. Siblings especially are encouraged to be present. Whilst watching their baby dying is very painful, it gives parents the comfort and satisfaction of being with their baby for the last time and this can help with the whole grief process ultimately.

The room is specially furnished to be as friendly and homely as possible. We hope to create an ambience that would allow family to have good memories of their loved one's dying.

Post-hospitalisation support programme

This programme involves a multi-disciplinary team of healthcare staff with the nurse, a member of the Neonatal Bereavement Support as the main coordinator. Parents of babies who died at the NICU or Special Care Nursery are contacted four to six weeks later, offering them an appointment for a follow-up conference.



The quiet room

This conference is conducted by the Bereavement support team consisting of:

- Attending Neonatologist who had cared for the baby
- Neonatal Nurse
- Medical Social Worker
- Other relevant healthcare personnel / specialist as necessary such the Obstetrician, Geneticist etc.

Matters discussed at the follow-up conference are:

- Overall view of infant's condition & care throughout hospitalisation
- Review autopsy findings if done
- Discuss implications for future pregnancies if relevant

Most importantly parents are encouraged to share their journey and coping with grief.

Neonatal bereavement support group

This support group is managed by neonatal nurses that aims:

- To provide support to families in loss and grief
- To understand the needs of grieving families and how these needs may be met

- To encourage quality care for families who are bereaved through developing partnerships with voluntary and statutory sectors.

The support group activities include:

- Home visits “just to keep in touch” with parents to maintain the rapport
- Attending the baby’s funeral as appropriate
- Sending out condolence cards to families
- Arranging for post bereavement family conference
- Remembering the anniversary of these children

Future plans

The Department of Neonatology is constantly striving to improve its services for bereaved parents and families and our plans are:

- To design pamphlets / information booklets for parents
- To involve parents who had experienced loss and grief in the support group activities to provide parent-to-parent support
- To help conduct memorial services for bereaved families to remember their beloved, departed children
- To plan and organise training and educational programs for enrichment of nursing / medical / paramedical staff providing bereavement support services
- To have a designated resource nurse to handle bereavement issues within the department

We hope to work very closely with Child Bereavement Support (Singapore) to achieve our plans.

Nameless Saints

The healing of the world
Is in its nameless saints. Each separate star
Means nothing, but a myriad scattered stars
Break up the night and make it beautiful.

– Baynard Taylor

ACKNOWLEDGEMENTS

We wish to express our heartfelt thanks to:

- All the parents who have shared their story with us; we appreciate the difficulty in remembering, and admire the courage you have in supporting CBS
- The doctors, nurses and healthcare professionals who have been compassionate and understanding in working with CBS
- All who have worked on officially launching CBS and producing this publication which we hope will bring some comfort to bereaved parents
- All who have helped with fundraising events to enable CBS to get started

Do not Stand at My Grave and Weep

Do not stand at my grave and weep,
I am not there, I do not sleep.
I am a thousand winds that blow.
I am the diamond glint on snow.
I am the sunlight on ripened grain.
I am the gentle autumn rain.
When you wake in the morning hush,
I am the swift, uplifting rush
Of quiet birds in circling flight.
I am the soft starlight at night.
Do not stand at my grave and weep.
I am not there, I do not sleep.
Do not stand at my grave and cry.
I am not there, I did not die!

– Mary Frye

APPENDIX 1

MATERIALS AVAILABLE FROM THE CHILD BEREAVEMENT TRUST, UK

Books

Caring—For You When Your Baby Dies

A comprehensive and general booklet guide written by a bereaved mother in the UK, with Jenni Thomas of CBT. Excellent advice and information.

Supporting Parents When Their Baby or Child Dies

A guide for professionals. This new updated edition will be available from May 2005.

Memories

A booklet with spaces for photos, foot and hand prints etc. Sections in the booklet allow for information of the lost child and for others to write “special words”.

This Is About Me

A workbook designed to help communicate difficult information to children when a parent (or prime carer) is terminally ill. Especially for 4- to 14-year-olds

My Book About Me

A workbook designed to help children with a life-threatening illness express their feelings, understand better and so lessen their concerns.

My Book About Our Baby that Died

A workbook for children to do with parents

Grieving—After the Death of Your Baby

A book to accompany the video (“When Our Baby Died”) aimed at helping families to find ways of expressing their grief and remembering their baby

The CBT Children’s Activity & Information Pack

A pack to accompany the video (“Someone Died—It happened to me”), full of information about children and grief, together with suggestions and ideas of things children can do to help them express their feelings. Included in this activity pack are notebooks to write thoughts; a balloon and a label to send a message; special stickers for writing or drawings; a glove puppet pattern and a book with information on losing somebody important in your life

Benedict—A Child of Mine

A small book of poems written by Alexa Warden, a bereaved mother.

Videos

When Our Baby Died

A video about grief for parents and families and all who care about them. Aimed at helping parents to feel less alone and to understand more about what they feel. Parents, grandparents and children talk about their feelings, explaining what the death of their baby has meant to them, and how it has changed their lives, and they describe some of the things they have done to express their grief, mourn for their baby and find support for themselves.

Someone Died—It Happened to Me

A video for children and teenagers about loss and grief. Children between seven and 18 talk about the loss of a parent, brother or sister.

APPENDIX 2

RECOMMENDED BOOKS

Guidebooks for bereaved parents

When the Bough Breaks: Forever After the Death of a Son or Daughter
Judith R. Bernstein, Ph.D.

After the Darkest Hour, the Sun Will Shine Again: A Parent's Guide to Coping with the Loss of a Child
Elizabeth Mehren

The Bereaved Parent
Harriet Sarnoff Schiff

The Worst Loss: How Families Heal from the Death of a Child
Barbara D. Rosof

How to Survive the Loss of a Child
Catherine M. Sanders

When a Baby Dies
Jill Worth

No Time to Say Goodbye
Paul Arnott

Empty Cradle, Broken Heart: Surviving the Death of Your Baby
Deborah L. Davis

The SIDS Survival Guide: Information and Comfort for Grieving Family and Friends and Professionals Who Seek to Help Them
Joani Nelson Horchler & Robin Rice Morris

Help, Comfort & Hope after Losing Your Baby in Pregnancy or the First Year
Hannah Lothrop

When a Baby Dies: The Experience of Late Miscarriage, Stillbirth and Neonatal Death
Nancy Kohner & Alix Henley

Healing a Parent's Grieving Heart: 100 Practical Ideas After Your Child Dies.
Alan Wolfelt

Trying Again: A Guide to Pregnancy After Miscarriage, Stillbirth and Infant Loss
Ann Douglas & John Sussman

Finding Hope When a Child Dies: What Other Cultures Can Teach Us
Sukie Miller

General bereavement guidebooks

When Mourning Breaks: Tales of Hope and Healing
Anthony Yeo (Singapore)

How to Go On Living When Someone You Love Dies
Therese A. Rando, Ph.D.

"You'll Get Over It": The Rage of Bereavement
Virginia Ironside

The Courage to Grieve: Creative Living, Recovery & Growth Through Grief
Judy Tatelbaum

To Heal Again: Towards Serenity and the Resolution of Grief
Rusty Berkus
(Short soothing statements with dreamlike illustrations)

Learning to Live Again: A Practical, Spiritual Guide to Coping with Bereavement
Rita Rogers
(Rogers is a well-known psychic practising in England. She gives compelling stories of putting parents in touch with their deceased children, helping them resolve some of their most painful grief issues.)

Grieving the Loss of a Loved One: A Devotional Companion
Kathe Wunnenberg
(A Christian guide)

Innocent Voices in My Ear
Doris Stokes
(An English psychic, famous in the 1970s and 1980s, writes about her special relationship and psychic communications with children and those who died young.)

Personal accounts of coping with the loss of a child

A Broken Heart Still Beats

Anne McCracken & Mary Semel

(This is a collection of pieces by famous people—writers, politicians, actors, other public figures both real and fictional—describing how they experienced the death of their child.)

Give Sorrow Words

Tom Crider

(A one-year diary following the death of his grown daughter in a fire)

Lament for a Son

Nicholas Wolterstorff

(Account of feelings and thoughts after losing a teenage son in a climbing accident)

Touching the Edge

Margaret Wurtele

(Account of healing process after losing her only child, a grown son)

Paula

Isabel Allende

A Grief Observed

C. S. Lewis

(A short but moving and expressive account of grief following the death of his much beloved wife)

A Grace Disguised: How the Soul Grows Through Loss

Jerry L. Sittser

(A heartrending account of grief and healing following a car accident which killed his child, his wife and his mother)

Philosophical approaches to understanding loss

Who Dies? An Investigation of Conscious Living and Conscious Dying

Stephen & Ondrea Levine

Life Lessons: How our Mortality can Teach Us about Life and Living

Elisabeth Kübler-Ross & David Kessler

The Wheel of Life

Elisabeth Kübler-Ross

The Tibetan Book of Living and Dying

Sogyal Rinpoche

No Death, No Fear: Comforting Wisdom for Life
Thich Nhat Hanh

The Journey Home: What Near-Death Experiences and Mysticism Teach us about the Gift of Life
Phillip L. Berman

Healing Grief
James van Praagh

Miscellaneous

Many Lives, Many Masters: The True Story of a Prominent Psychiatrist, His Young Patient, and the Past-Life Therapy that Changed Both Their Lives.
Dr. Brian Weiss

Life After Life
Raymond A. Moody

Death's Door: True Stories of Near-Death Experiences
Jean Ritchie

Words of Comfort
Edited by Helen Exley
(Little hardcover booklet containing collection of grief poems)

When Your Friend's Child Dies: A Guide to Being a Thoughtful and Caring Friend
Julane Grant

The Christmas Box
Richard Paul Evans

Helping children cope with grief

On Children and Death: How Children and their Parents Can and Do Cope with Death
Elisabeth Kübler-Ross

The Kid's Book about Death and Dying: By and for Kids
Eric E. Rofes and the Unit at Fayerweather Street School

I Will Remember You: A Guidebook Through Grief for Teens
Laura Dower

What on Earth Do I Do When Someone Dies?
Trevor Romain
(Guidebook written for young children answering their most common questions)

farewell, my child

Sad Isn't Bad: A Good-Grief Guidebook for Kids Dealing with Loss
Michaelene Mundy

The Fall of Freddie the Leaf: A Story of Life for All Ages
Leo Buscaglia, PhD

Lifetimes: A Beautiful Way to Explain Death to Children
Bryan Mellonie & Robert Ingpen

Badger's Parting Gifts
Susan Varley

No Matter What
Debi Gliori
(For preschool children)

Someone Special Died
Joan Singleton Prestine
(For very young children)

Shooting Stardust
Frrich Lewandowski
(Story for young children told by a boy whose brother died)

Balloons for Trevor
Anne Good Cave
(Story of a boy who loses his best friend, told for school age children)

When Someone Dies
Sharon Greenlee

Jack's Journey
Laura Harris, M.Div, MSW & Steve Dawson M.Div, LCSW

Water Bugs & Dragonflies: Explaining Death to Young Children
Doris Stickney

When Dinosaurs Die: A Guide to Understanding Death
Laurie Krasny Brown & Marc Brown

APPENDIX 3

RESOURCES

Websites

Child Bereavement Support (Singapore), www.childbereavementsupport.org.sg

The Child Bereavement Trust, UK, www.childbereavement.org.uk

The Compassionate Friends, www.tcf.org.uk

- An international network of bereaved parents (who have lost children of ALL ages), providing information, support and friendship via e-mail

MISS Foundation, www.missfoundation.org

- A US based organisation providing support to families who lose a baby or young child

Malaysian Momshare, www.geocities.com/malaysianmomshare

- This is a Malaysian based site (with members living in both Malaysia and Singapore) set up by the pioneering Lilian Chan, providing support and friendship through an active email network

Foundation for the Study of Infant Death (FSID), www.sids.org.uk/fsid

- A UK charity working to prevent infant deaths and promote baby health, providing a telephone helpline, information and an excellent network of “befrienders”

Child Death Helpline, www.childdeathhelpline.org.uk

- A UK based helpline, staffed by bereaved parent volunteers, for all those affected by the death of a child (at any age)

Emedicine, www.emedicine.com/emerg/topic691.htm

- Informative articles about grief on the death of a child

BUPA, hcd2.bupa.co.uk/fact_sheets/html/coping_death_child.html

- Articles about coping with grief when a child dies

SHARE – Pregnancy and Infant Loss Support, www.nationalshareoffice.com

- A US based organisation providing support to those who lose a baby through early pregnancy loss, stillbirth or newborn death

Twins and Multiple Birth Association (TAMBA) Bereavement Support Group, www.tamba-bsg.org.uk

- A UK based organisation offering parent to parent support for the loss of one or more twins or multiples

IVF Connections, www.IVFconnections.com

- A comprehensive website for parents undergoing IVF treatment, also including the loss of a child through early pregnancy loss, stillbirth, newborn death or young children

Counselling centres in Singapore

The following are counselling centres open to anyone, regardless of race or religion. They offer general counselling services, including bereavement counselling.

Centre	Tel. no. (as at March 2005)
SINDA	62985911
Shan Yu Counselling Services	67419293
PPIS (Jurong)	65613462
Moral Family Service Centre	64491440
Counselling & Care Centre	65366366
Care Corner Family Service Centres:	
Toa Payoh	63561622
Woodlands	63622481
Admiralty	63658751
Queenstown	64761481
Care Corner Counselling Centre (Mandarin)	63531180
Saint Andrew Life Streams	63232902
Help Every Lone Parent (HELP) Rainbow Programme	64162162
LP Clinic (Mount Elizabeth Hospital)	67354526
Family Works Pte Ltd	62353341
Elizabeth Dickinson (Maximum Potential)	6254 9404

Others

A comprehensive guide on formalities and procedures immediately after death, called *When A Loved One Passes Away*, has just been published jointly by the National Environment Agency and The Association of Funeral Directors (Singapore). This is available free of charge from all hospitals in Singapore.

LAMENT (excerpt)

The void that fills our house is so immense

Now that our child is gone. It baffles sense:

We are all here, yet no one is; we feel

The flight of one small soul has tipped the scale.

You talked for all of us, you sang for all

You played in every nook and cubby hole.

You never would have made your mother brood

Nor father think too much for his own good;

The house was carefree. Everybody laughed.

You held us in your arms: our hearts would lift.

Now emptiness reigns here; the house is still;

Nobody ever laughs nor ever will.

All your old haunts have turned to haunts of pain,

And every heart is hankering in vain.

– Jan Kochanowski

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