



another baby?
the decision
is yours

A booklet for parents whose baby or young child
has died and who are considering having another child.

sids^{and} kids

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Another baby? The decision is yours

The death of a child is perhaps the greatest tragedy that can occur to parents. You will be changed by this devastating loss and you may find that your previous thoughts and plans about having another child will now also be affected.

- You may be wondering when, or whether, you should have another child.
- You may be surprised by some of your own feelings and wonder if other parents have felt the same way.
- You may notice that you and your partner feel differently about whether and when to have another baby.
- You may be given advice by family, friends and others who have your best interests at heart, but the advice may not seem right.

It is important for you to know that:

You and your partner are the only people who know what is right for you...so have the confidence to believe in your feelings.

There is absolutely no right or wrong decision, only what is right for you. However, no matter what your decision is, there will be times of doubt, hesitation, fear and joy, and you may change your mind several times.

This booklet aims to reassure you that no matter how strange your thoughts and feelings may seem, other parents have probably had similar thoughts and feelings.

“I remember, after Daniel died, receiving much unsolicited advice from various sources: ‘The best thing you can do is get pregnant right away; have another baby’. Alternatively: ‘You have to give yourself time to grieve for your baby; don't try and replace him with another’. Naturally I resented being told what ‘the best thing’ for us was.”

“I had made the decision to have another baby within 24 hours. I wanted to know if that was normal.”

“Any final decision is only final for today, tomorrow you may feel very different.”

Thinking about having another baby

Your baby has died but the love you have for him or her will not end. It is precious and enduring; he or she will always be a part of your family. In thinking about whether to have another baby, you may be afraid that you are being disloyal or that you may come to love that precious child less, but this will not happen. Every child is unique and special and your love and memories will always remain - another child will not diminish this in any way if you choose to have another child.

The famous psychiatrist, Sigmund Freud, after the death of his daughter, Sophie, wrote to a friend:

“Although we know that after such a loss the acute state of mourning will subside, we also know we shall remain inconsolable and will never find a substitute, no matter what may fill the gap, even if it be filled completely, it nevertheless remains something else. And actually this is how it should be...it is the only way of perpetuating that love which we do not want to relinquish.”

(Freud, S. (1929) Letter to Binswanger. In E.L.Freud (ed.) Letters of Sigmund Freud, New York, Basic Books.)

Many parents are very frightened about having another baby after one of their children has died. There is an incredible feeling of vulnerability. There is a realisation that parents are not able to control everything about their lives and the lives of their children. No matter what the cause of the death, any situation that is a reminder of the cause of death evokes special anxiety.

We decided to have another child

It takes courage to contemplate having another baby after a child has died. You may have many fears and uncertainties: Will this baby be all right? Will he die too? How will I sleep at night? Will I be able to love another baby? Is it worth the risk?

These doubts and uncertainties are not unusual. You have been touched by tragedy. The unbelievable has happened, your sense of security and safety has been shattered and you are vulnerable.

“The day Mitchell died I decided that I wanted another baby. Today. I didn’t want to replace him, I just wanted a baby. A baby to hold and cuddle.”

“I wanted other children before Sam died and I’m sure Sam would want me to fulfil my dreams after his death, as I would if he was alive.”

“We loved our son. We loved being parents. We knew we would never have Daniel back, but we could have his brother or sister - and that was an exciting thought.”



“The joy of holding my beautiful live daughter was a blessing I thought I would never know again.”

“We could never replace Alyce but we needed another baby to cuddle. Renée was born one year later. She brought us back to life. It was the best decision we ever made for ourselves and for our [older] daughter, Sara.”

“We learned...that a very large percentage of [bereaved] parents decide to have another baby. I think this gave us some encouragement also.”

“We wrote all the ‘pros’ and ‘cons’ on a sheet of paper. There was soon a long list of ‘cons’ but it was difficult to write any ‘pros’ at all, beyond our heartfelt longing.”

“Looking back, I know that we made the right decision to have her. If I had waited maybe I would still be trying to make up my mind today and I would have missed out on her special way which is helping to ease the pain...”

“At time of writing, Simon is 20 weeks old and thriving... Our confidence and pleasure in our baby are growing, despite all the usual strains of living with a young baby and the added worry that death may strike again. There have been some difficulties and inconveniences but we have never regretted our decision to bring our beautiful baby into the world.”

Some people will decide that, for them, the right decision is not to have another baby. It may be that anxiety is overwhelming, that there are physical barriers to another pregnancy, that family relationships have changed, or simply that it is not right at this time.

There may be thoughtless comments and pressure from friends and family to have another baby and the decision not to do so takes courage and should be respected.

“We are so thankful for the four very short months we had with her and the wonderful memories, but our lives have changed now and our decision [not to have another child] reflects our feelings from this change.”

“Time does heal even if you don’t have another child.”

“... We made the decision not to have a subsequent baby just now. The decision was a hard one to make.”

“I felt that another child could not close the black hole in my heart.”

Postponing the decision

If the decision is too difficult to make, or if you and your partner are not in agreement, you may feel that it is better to postpone making the decision. For a whole range of reasons, it may be that this is not the right time for you to have another baby: you may feel your life is too unsettled or you may have too many other demands.

“The choice wasn’t there as an option - whether I would or wouldn’t. As a single mum, I felt I couldn’t.”

When the choice is taken away

It may be that you have no choice about whether to have another child because of genetic concerns, irreparable injury to the mother at the birth, a vasectomy, or some other cause. This loss of choice can cause additional grief, and you may find it helpful to speak with someone else who has had a similar experience and/or to a counsellor.

“I wanted an acknowledgement that sometimes the decision may be taken out of your hands. You may decide not to have another child, but I haven’t decided that at all. The decision has been taken away from me...it is the loss of power and choice that is difficult to deal with.”

“From six pregnancies I only have one living child. After the death of my last child, Zoe, I lost all confidence in my own physical and emotional resources to have another child. Doctors could not explain why my generally strong, fit body could not prevent early deliveries. My marriage was struggling and I had little faith in my husband ‘being there’ for me during another pregnancy. It wasn’t fair on my daughter to go through it again. Very very gradually I learned to accept that she would be my only child and that I should try to heal myself through meaningful work and purpose, in helping others.”

You may be pregnant when your baby dies or you may find yourself pregnant earlier than planned. Probably you will feel confused and anxious, perhaps thinking “we are not ready for this... we are mourning our dead baby”. At the same time you may be scared, anxious, hesitant, ambivalent and also possibly excited about this new baby.

“I was glad that we were already pregnant when Courtney died, as I didn’t know if I could make the decision to have another baby. But with time it helped and we had two more babies after Courtney died.”



“Although I conceived only two months after Sam died, I didn’t feel ready. But I felt that time would heal and hoped I would be ready when the baby was born.”

“I felt that I needed to regain some hope for my shattered family but I was staggered to think I could fall pregnant 6 weeks after our son’s death. I drove home from the doctor’s crying ‘I’m so sorry Simon’. I was always worried people would think I’d got over losing Simon - I most certainly hadn’t.”

“I was already pregnant when Jade died. I don’t remember many good times during the pregnancy - we were so afraid. But looking back, I wouldn’t change it. Corey helped us to survive.”

“Just 10 months after the death of Chloe I’ve found out I’m pregnant again. I have only known for three weeks, but have thought about not going through with it so many times. But I have decided I will.”

Each State has different laws for adoption and permanent care. Unless you are infertile and under 35 years, it is most unlikely that you will be able to adopt a healthy baby. However, there are many other children, older than 4 years, or with special needs, needing families. In addition, inter-country adoption may be a possibility for you.

While it is important for any subsequent child to be wanted for his/her own sake (rather than as a replacement), this is absolutely crucial for an adopted child, who will have had his or own experience of loss, of birth, family and identity.

“I often wondered if I would have had as much trouble bonding with my own biological child – was it the fear of this child dying too? In time I came to realise that it was my coping mechanism and that I probably distanced myself from all my children a little at that time.”

Older parents

It may be that you had not considered having another child until the death of your child, that your family was complete. The consideration of whether to have another child may mean an upheaval of all your plans and you may feel pressure to make a decision quickly if you are nearing the end of childbearing years. You may be worried that you will not be able to conceive again, or that you are taking a risk in doing so. It may be wise to consult your doctor if you are concerned.

Special issues for fathers

Sometimes mothers are anxious to have another child more quickly than fathers. If you are not in agreement, it will be important to discuss your thoughts and feelings openly and honestly in order to work towards agreement, as you will need each other's support if you decide to have another child. For both men and women, there will be an increased sense of risk and an awareness that something could go wrong with this pregnancy.

Men may express their grief differently to women. Some women comment that their partners do not express their grief as openly as they do, and family and friends tend to offer more support to mothers than fathers, since outwardly they seem to be fine. They may escape from reality at work, but their grief is just as real and deep. After the death of a child, fathers may feel a sense of guilt or failure in their role of 'family protector', and regret wasted opportunities:

"If I had known that we had so little time with him [Ben], I would never have gone back to work."

"We got pregnant the month after Ben died. We didn't know what to feel – excited, guilty, scared...I miscarried at ten weeks and felt totally vulnerable, totally fragile. I felt that the universe was out to get me and my family. I decided at that point that I didn't want another child – the pain was just too great! It was Michael who said 'Everything really good in life involves some level of risk. Are you prepared to take a risk to achieve an amazing end?'...Along came Gemma nine months later. She was and is our gift from God. She restored our faith in the world. She helped to teach us to laugh again. She gave Michael the opportunity to enjoy every aspect of her. She gave him an outlet to express all that he would have liked to have given to

Ben. She helped to fill a very big void in the core of his being. His face lights up when she comes into the room.”

“After five miscarriages, I didn’t realize how much it had affected my husband until our baby was born alive. Now my husband doesn’t want to try any more and I have to respect his position.”



Special issues for siblings

Your other children

Your other children will be very deeply affected by the death of their brother or sister and will be grieving in their own way. It is natural that they will also have thoughts and fears about another pregnancy and it is likely that they will ask you direct questions about whether this next child will die too. Their thoughts and fears should be respected and acknowledged openly and honestly. In fact, you should expect that siblings will have questions for years to come, as they grow older and as their understanding grows and develops.

Some parents have suggested that after the birth of a new baby, it is important to consciously make a point of including your existing children, giving them time and attention. It is easy to be so preoccupied with a new baby that existing children may feel excluded.

“When I listen to other people’s children who have had a child die it seems that they have a much bigger understanding that babies and children can die. Children in the general community wouldn’t even consider asking about it, but they seem to take it in their stride, accepting that this is a possibility.”

“To this day, not a day goes by (3 years later) that my older children (now 11 and 9) do not make some reference to Ben in some shape or form...I did consult my other children when we were deciding whether to have another baby. I had to think what impact this would have on them, because they are very vulnerable people...even though they understand a great deal more than other children.”

“When our next child was born our 13 year old laughed! I realised that I hadn’t heard him laugh for 2 years [since Philip’s death].”

Children’s fears:

5 year old Darcy: *“Mum, if this baby doesn’t die while you are giving birth, and if this baby doesn’t die later, we will be really lucky, won’t we?”*

3 year old Amelia: *“I really miss Lily. This next baby is a girl!”*

7 year old Nathan who wanted his Dad to acknowledge his fears: *“Dad, if this baby dies too, are we going to put up a photo of this one too?”* Father replied: *“No this baby’s not going to die.”* Nathan: *“Dad, you’re not listening.”*

An issue that concerns many parents is how subsequent children can feel a connection with a brother or sister who died before they were born. Things such as photos, belongings, and videos make good opportunities for

discussions and memories to be created. Some parents have written stories for their subsequent children that make a link between them and their brother or sister who has died. (SIDS & Kids Victoria have available copies of two stories: *Star Babies* by Sharon Faulkner, and *Gumba's Garden* by Mel Ryan.)



The pregnancy

It is possible that you will have fears and anxieties at times throughout the pregnancy. At times you may feel you are going crazy. You may be afraid of having the same problem again, or you may now have a heightened awareness of a whole range of other possibilities: miscarriage, stillbirth, SIDS, an accident or sudden illness. And you may be afraid of being happy, or of not being able to love this next baby.

This is quite normal as you have already experienced an overwhelming sorrow, so your sense of security and confidence may well be undermined.

For parents whose first child has died, you may question your ability as parents. You will need support and encouragement to develop your confidence again. It may be helpful to discuss your fears and anxieties with your doctor or midwife, and possibly also with your child health nurse.

Sometimes anxiety can be reduced by changing hospitals, doctors and child care practices, or by having scans and tests that might alert you to possible problems during pregnancy. You could discuss these with your doctor. You may also find it helpful to create a special project for the new baby – paint a mural on the nursery wall, redecorate the cot, change rooms, or other ideas.

Planning a due date

Some parents find it best to try to avoid a subsequent baby being born on or near their dead child's birthday or the anniversary of his/her death.

“I refused to try in the December...because I didn't want another child born in September. (Phillip's birthday was the 24th.) After that, we tried in earnest.”

“We set ourselves a time limit. We would continue using contraception until early December to avoid having a child born around Eliot’s birthday or the anniversary of his death and to try and avoid having a winter baby. We agreed to stop trying in two years time if we had no success because my age would increase pregnancy risks.”

The sex of the baby

“I was obsessed with having another boy. I had even said to people that if the baby was a girl I didn’t know if I would be able to love it. They were horrified that I could even think that way but that was how I felt....I was so glad and relieved when it was a boy.”

“Another girl! We were absolutely ecstatic...both of us deep down wanted another girl.”

“When I was about 18 weeks I went for my scan...I asked what sex the baby would be. The radiologist said ‘Do you really want to know?’ Because of my hesitation she refused to tell me. I went away and cried over a cup of coffee and then decided I did really want to know. The radiologist told me I was to have a girl. Again the tears flowed before I could even thank her, but in hindsight, at least by the time Emily was born I had adjusted to the fact that I was not to have a son.”

“In the midst of our pleasure we only sometimes felt disappointment that our hopes for a girl were not fulfilled.”

“When the results of an amniocentesis came, nothing abnormal was detected and it was a girl! I was ecstatic but Ross was devastated – his dreams of playing cricket with two sons were shattered. It was not until that point that I realised that Ross and I had different needs from this pregnancy.”

“I was devastated to learn I was to have another boy, as I thought that it would happen again to my new son but it hasn’t and I’m happy with my little man.”

Pregnancy after a stillbirth or neo-natal death

Many parents have intense thoughts and feelings during their pregnancy following a stillbirth or neo-natal death. If your baby died before or soon after birth you will probably have few memories of your child and you will be grieving for all the hopes, dreams and expectations that you have lost with the death of your child. It is likely that your anxiety may be heightened during the next pregnancy especially as your baby reaches the gestational milestones of the baby who died. You will have a greater awareness of some of the things that could possibly go wrong. You may feel acutely aware that, although this is not your first child, you may not have the experience of parenting a live child.

It is particularly important that you have trust in the health professionals caring for you since the memories of the care you received after the death of your baby will be vivid. Try to ensure that you find good support and someone to share your thoughts and feelings with.

“I was desperate to get pregnant and when it happened I thought, ‘Now I’ve got this rollercoaster ride again’...It’s a terrifying experience to find out you are pregnant after you’ve had a baby die.”

“I thought, ‘It’s not going to happen, this baby will die soon.’”

“Every time I went to the obstetrician I insisted on an ultrasound to check the baby’s heartbeat. I was convinced the baby was dead. On the other hand, I couldn’t look at the screen to see the heartbeat... When I was in labour, I said to myself, ‘Calm down, don’t get excited. It’s going to be dead!’”

“Through your grief you learn how to parent a baby who has died and you don’t know how to parent a live baby. I became twice as paranoid: I didn’t know what to do.”

“Passing the anniversary of the gestational age that my baby died didn’t make it easier. I felt more insecure. I never really felt safe. Perhaps it’s a bit like passing the first year anniversary – you don’t always feel better.”

“I grabbed my obstetrician and said to him, ‘Don’t you let my baby die.’”

“I appreciated the honesty of my doctor when he told me that he couldn’t guarantee outcomes.”

“The way staff manage the subsequent pregnancy is very important. I told [my story to] everyone in the hospital and I felt they ignored me a bit because it was too hard.”

The birth: grief and joy

The birth of your next baby will almost inevitably re-awaken your grief for your child who has died. It will be a time of sadness, grief, joy, pride, relief and probably anxiety.

“I cried for the first 24 hours when my daughter was born. They didn't understand that I was actually saying goodbye to my dead son.”

“When my next son was born I cried and cried. I realised it was really saying goodbye to Jonathan with the arrival of a new son. At some level I must have still thought that he was coming back but the new baby was his own little person.”

“When Jonathon was born I insisted that he stay by my bedside continually. I got no sleep and my milk was late arriving. I felt that no-one in the world understood what I was going through.”

“It is difficult to be feeling two opposite emotions at once. Such joy at the new life, the new hope, the new chance, intermingled with such grief and pain at the lost life, lost hope, lost chance.”

The hospital

Parents often find it helpful to visit the hospital and meet the midwifery staff before the birth. You could talk to them about your feelings before you go into hospital for the birth. On the ward, make sure that staff know about your story; a note on the top of your history may help. Ask for continuity of staff if possible, to avoid constantly having to tell your story to new staff. Don't be reluctant to ask for whatever special arrangements will help.

“I think that it is important to inform staff how you feel and maybe even request a single room if that is what you feel you need. I did this because I was unsure about how I would feel after the birth of our subsequent child. I know I wanted privacy and I didn't want to frighten other mothers if I was a crying mess.”

“I think it helped that I wrote my story for the midwives to read – it seemed to really help the staff.”

Some parents will find it difficult to trust anyone else to care for their baby in hospital, whereas others will find it frightening to have the responsibility, particularly whilst their baby is asleep. Both reactions are understandable and based on a very normal fear. Hospital staff need to know why you are feeling this way. Do talk to them.

“Being in labour in hospital the staff were telling me to push and I said ‘No, I've changed my mind. I'm not having the baby today. She is safer inside’...I was in labour for 30 hours!! Lucy was born beautiful and well...Finally!!”

“I felt very anxious in the fortnight prior to the birth. I had a deep fear that the baby might not survive the birth and actually asked for a caesarean to end the worry.”



The new baby

Your new baby will bring joy but maybe also sorrow, as you remember the older brother or sister whom he or she will never know.

You may initially find it more difficult to feel a special bond with this baby. Many parents worry about allowing themselves to get close to or love their new baby too much, for fear of being hurt again. Usually this passes fairly quickly, as you get to know your new child. Sometimes people find that after their new baby has passed the age at which their other baby died, they seem to feel more relaxed and are more able to enjoy this new baby. However, this may not be a comfort for people whose children were older when they died.

You may also feel scared. This is normal. Even people who have never experienced the death of a child will feel frightened by the responsibility of a new baby, so it is to be expected that you will feel afraid at times!

“I initially held back from loving too much to protect myself ... for fear of being hurt again or of losing her.”

“Initially, my husband would check our sleeping baby constantly but I would never go and check particularly if she overslept. I always felt that if she was dead I wanted to postpone the agony of finding out. It is something I still cannot do.”

“I was surprised and unprepared to find that I grieved for Jacob all over again following Luke’s birth – Jacob should have reached the milestones Luke was reaching, Jacob would have been as adorable as Luke. Jacob should have grown and flourished as Luke was.”

“Once the baby started to move inside me, I started to panic. I was frightened. I quickly convinced myself that I had never really wanted another baby. I felt that I would be unable to hold it, love it, breastfeed it or care for it in any way.

However, I couldn't stop myself from loving him, holding him and caring for him in every way."

"Because Zoe died when she was 20 months old, we didn't sleep properly until Lily was well over 2 years."

"I also remember feeling so angry at times. It was bad enough that Jenny had died, but living with the fear that it could happen again seemed to be so unfair. The fear did seem to increase as the 10 week mark approached [the age that Jenny died]. The night that Allison was the same age as Jenny had been, was one of the hardest."

"How many children do you have?"

It is probably a good idea to plan how you will answer questions from strangers who do not know about your child who has died, questions such as "Is this your first child?" You may feel more in control if you decide beforehand what you will tell strangers.

"Personally I feel I need to acknowledge Julia (our baby who died) even more so after the birth of Matthias."

"I choose who I tell. Sometimes I say I have four children, and sometimes I say I have had five. I am only interested in talking to people that I feel comfortable with, about my child who has died."

Comparisons

It is normal to look for similarities and differences throughout the pregnancy and when the new baby arrives. If your child had not died you would certainly have compared a new brother or sister to them. You will still do this and when others compare them too, it will reassure you that your child is not forgotten.

“I was pleased at how much Kaitlyn looked like Daniel. Not identical, but she looked like his sister.”

“No-one in the family, not even my husband, could see a resemblance between my lost Geoffrey and my new Jonathon. No-one wanted to acknowledge that Geoffrey had ever existed. But I knew that Geoffrey was very special and he would always live in my heart.”

“I never realised how soft a baby’s skin is and how wonderful that baby smell is until after Jenny died. Allison and Christopher brought back those smells and touches.”

Choosing a name

You will be conscious that this next child has his/her own distinct identity. Occasionally parents make a link with the child who has died by including that child’s name as a middle name. There is no rule about this.

Your child's belongings

Some parents decide to keep in a special place a selection of the clothes and toys that belonged to their child who has died. The remaining items then might be used again for the next child, or given away. There are no right or wrong choices about this – do whatever feels right.

“We had decided that we wanted as many things different from when we had Mitchell as possible. For example Jacob slept in the same room as us. Mitchell slept in his own room. Mitchell had slept in a bassinette. Jacob slept in a cradle. Jacob and Mitchell were born in opposite seasons so I didn't have to face the issue of Jacob wearing Mitchell's clothes. I did however use the same nappies, singlets etc.”

“I had made a couple of quilts for Daniel and was happy to use these for the other babies. Likewise, with many of his toys. But a couple are kept out of reach and remain Daniel's.”

“As Megan died at the age of 4 months, a lot of her clothes were never worn. However she did have some special dresses...we decided that Sarah would not wear these.”

“We decided not to use any of Joshua's belongings for Trent, as Trent was a new person and had to have his own clothes, bed, etc.”

“Our new daughter wore some of Zoe's clothes, just as she would have if Zoe had lived. It gave me a sense of continuity within the family.”

Sleeping your new baby safely

If your child died of SIDS or from some hazard in his/her sleeping environment, you will be concerned to have up-to-date information about how to reduce the risks of SIDS and ensure that your child's sleeping environment is as safe as possible. Research has provided good practical ways that you can reduce the risk of SIDS, but it is important to remember that risk factors are not causes; the causes of SIDS are still unknown. There is no way of knowing whether any of the risk factors play a part in any one child's death.

Your local SIDS & Kids organisation has brochures which provide information about ways to reduce the risk of SIDS and to prevent sleeping accidents by focussing on safe cots, safe mattresses, safe bedding and a safe sleeping place.

Suggestions about providing a safe sleeping environment may raise anxieties and possibly even feelings of guilt over the death of your child, but you need to know that this information is new and may not have been available to you. Some deaths just cannot be prevented.

“I felt very strongly that the only way I could enjoy my next child to any extent was by taking every precaution I possibly could.”

“I did my best with Kara with the knowledge I had. With my subsequent child I am aware of the risks even more so and I do my best with the knowledge I have.”

Monitoring

Some parents find it reassuring to have an intercom between rooms monitoring noises in a child's room. These intercoms are for reassurance and allow parents to be responsive to children who are in another room. They are not used for monitoring breathing or sleeping position.

Parents who have had a child die suddenly and unexpectedly may make enquiries about the use of monitors to detect the possibility of a cessation of breathing. An apnoea monitor is a piece of medical equipment, which detects changes in a baby's breathing pattern. Apnoea is a medical term which means that breathing has stopped. It is known that short periods of apnoea are normal in infants.

There is no evidence that using an apnoea monitor prevents SIDS, or that there is any scientific benefit from the monitors. Some parents may feel more relaxed and reassured using a monitor for a subsequent child, but others may find that using a monitor increases their anxiety, especially if "false alarms" are often experienced.

More detailed information on monitors can be obtained from your local SIDS & Kids organisation. It is important if you do decide to monitor that you contact a recognised hospital-based Home Apnoea Monitoring Program so that you have technical support and learn how to perform infant resuscitation in case you should need it. Your local SIDS & Kids organisation can advise about this and can arrange for you to speak with other parents if you wish.

“We knew a monitor was not a lifesaving device. We wanted to focus on ‘the positive’ and for our new baby to be part of our family in as normal a way as possible. We were afraid the technological intrusion of a monitor would inhibit the adjustment process for all of us.”

“Living with a monitor can be challenging. Looking back, I realise how silly some of the things I did may have seemed to someone else. Like having a shower with the door propped open and the control box up on the bed, so I could see the little green light. I knew from experience that I would hear the alarm even with the door closed, but it was ‘just in case.’”

“We decided before I had even conceived that we would have a monitor...It would give us more of a feeling of control and that if he did die we had done everything we possibly could.”

“I wouldn’t walk into the room if I couldn’t see that light flashing...I couldn’t put her (next child) in a cot without a monitor, because Ben died in a cot.”

“We decided against a monitor...we became our own monitors though. Kaitlyn went everywhere with me during the day. She was wheeled from bedroom to bathroom to kitchen to laundry to lounge – awake or asleep. She wasn’t left with anyone else until well over 12 months and slept in our room until she was nearly two.”

“We monitored James, Andrew’s surviving twin. The monitor instantly became a family friend. Patrick, our subsequent baby was also monitored – even in hospital – again with a feeling of real relief. Monitoring was a really important issue for our older children who were young teenagers. It lessened their anxiety enormously.”

What people say

The death of your child has also affected friends and relatives. They may feel worried about you and the new baby. Sometimes they will not know what to say or do and sometimes their comments may hurt. But do try to keep your friendships going – don't let barriers arise between you. You are the 'experts' about your own family, so you are the ones to make the decision about whether and when to have another child.

Occasionally, if friends and relatives have no knowledge about grief and loss, they may assume that your grief will disappear and you will be fine again when a subsequent child is born. They may need a gentle reminder that you are not replacing your child who has died and that your love for that child, and your grief, will always be a part of your life.

“We always wanted a large family, but we didn't know what other people would say if we had another child. We worried too much about what other people would think. Other people don't understand what we are going through.”

“Our parents especially were not overjoyed at the news that we were pregnant again. They were scared for us because they had no control over what may happen again. However, in hindsight I can understand their concerns. They do not regret our decision now as they have a beautiful healthy grandson that they adore and cherish.”

“Some people, who were really close to us, said we were not ready to have another baby. I realised that they actually meant that they were not ready to take that risk of loving another one of our children...but now they share in the joy the children have brought.”

“I will never forget someone very close to us saying how disappointed they were in us. That made me very angry but all the more determined to be happy and make it work.”

“The infant welfare sister would ask ‘Is she sleeping through the night yet’ and I would say ‘No and I won’t let her’...She sleeps through the night now – she’s 6.”

“It made me upset when people presumed we would be disappointed when all our subsequent children were girls, after losing a boy. All we wanted were happy, healthy children.”

Final thoughts

You may find it helpful as well as reading this booklet to talk to other parents and/or to a counsellor. Whatever decisions you make, it does not mean you have stopped grieving for your child who has died. Your child will never be replaced, but you will learn to build your life around your loss. A future with new hopes and dreams is possible.

“Time does heal even if you don’t have another child.”

“When Jemma was born I laughed from my heart again for the first time since Justin died...I found out what healing means when [she] was put on my tummy after she was born.”

“What we needed the most was counselling and support for us with other parents in the same situation. A new baby/pregnancy for grieving parents is not filled with joy and happiness that so many other parents feel...Having

other parents around who are either in the same situation or have been through it before gives you some hope that there is a light at the end of the tunnel.”

“It has been a long hard road at times but for every day we miss our beautiful boy we are faced with another equally adorable child who brings us endless joy. She has helped repair some of the damage of a devastating loss. To be blessed with her has been worth every minute.”

The documentary ‘Regarding Raphael’ screened on ABC TV’s Australian Story in 2002, is Vanessa Gorman’s story of the birth of Raphael who was born two years after the death of Layla, her daughter who died soon after birth. Layla’s father, Michael Shaw comments:

“Probably what people really want to hear is, ‘She was sad, she had the baby and now she’s better’, and it’s not how things are. It’s just not how things are, you know. One child doesn’t replace another one.”

Vanessa reflects:

“I want the opportunity sometimes still sort of to say ‘I really miss her, you know. I just really miss her.’ And it’s so simple and basic. But I still miss her every day, and I still think about her every day... It can never really be a happy ending when you’ve lost your child because that loss is always there, but it’s a happier reality I guess...Raffie - I feel like he’s given me a future. I feel like he’s given me back optimism in the world and optimism about life. I’m so looking forward to seeing him grow up and seeing all his little milestones and his big milestones...And so he’s given me back optimism and joy. Huge gifts.”

Parents' stories

Our son, born May 2001, lived for 5 days. Our daughter, born October 2002, is now aged almost 5 months.

I had a miscarriage in May 2000 which made us very unhappy. We were delighted when I got pregnant again later that year. Our baby was due in early June 2001 and the pregnancy was an apparently normal, healthy one.

At 38 weeks, 3 days after having had a normal routine check with my obstetrician, I suddenly noticed the baby's movements cease. My husband rushed me to the hospital where I was found to have very high blood pressure and was diagnosed with severe, sudden-onset pre-eclampsia. The placenta was assumed to have suffered a serious restriction of the blood supply in the previous few hours. This would have cut the baby's oxygen supply down dramatically. He suffered from further asphyxia during the time taken to stabilise my blood pressure for an emergency caesarian section. He was born that morning, weighing 2.36 kg. He was born looking perfect (and beautiful), but he was in fact very sick, and he died 5 days later, in our arms. Although his life began with some hope, we knew for about the last 3 of those 5 days that he would die.

It goes without saying that this time, and the months that followed, were the most awful in our lives. Our lives are changed forever, and we do not look at the world, or the people in it, in the same light as before. There are many tragedies in the world, and the death of a desperately loved little baby, and the fear that he has suffered, is one of them.

I knew before our son died that I wanted another child, and as soon as possible. Before a fortnight or so had passed my husband felt the same. I felt guilty even thinking about it when we had not even had our son's funeral. At first we were afraid we might be advised not to have another child. Apart from the damage pre-eclampsia could cause to another baby, it had almost killed me. My obstetrician saved my life: he reckoned I was about 6 hours from a coma. I was desperate to have another child (if having our son back

was not possible) – this was more important to me at that time than to my husband, who felt we still had each other.

After many tests we were given a 25% chance of a recurrence of this type of pre-eclampsia with every subsequent pregnancy. This doesn't sound very promising, but we were enormously encouraged! I was advised to wait a year before trying to get pregnant again, to allow my kidneys to recover (without which the pre-eclampsia was more likely to recur). The months that followed were awful for us both, and I had no focus and pretty little interest in life. I felt as though my body had killed our son. At times I felt as though I wanted to die with him. I was very angry about pre-eclampsia and the lack of knowledge and discourse about this devastating condition. I did everything I could to find out about pre-eclampsia, management and outcomes. I was angry with women with healthy children who would casually say 'oh yeah, I had pre-eclampsia' and angry when they didn't understand that my pre-eclampsia had not been mild, or gradual, or of a nature to be manageable even by an expert obstetrician. After going through a short phase of wanting to talk about our experience, I clamped up. My husband would not discuss it with anyone but me.

We formed new views of our friends and family: some rallied round, and we had marvellous support from unexpected quarters, yet others disappointed us bitterly – and still do. We were made to feel as though we were a weird breed of outcast: childless parents. At times I was treated as if I had never experienced pregnancy or motherhood. If it weren't for my mother, my sister and a few others, I would feel as though our son had never lived. My mother and sister in particular do everything they can to keep his memory alive for us.

Amazingly, after 9 months my kidney function tests were normal and we were given the 'green light' – miraculously our daughter was conceived within a couple of days! It gave me the feeling that she was really determined, right from the start. During the pregnancy our feelings were an odd mix of hope and optimism on the one hand, and anxiety and fear on the other. We could

not even imagine ever being able to bring home our own baby. All we wanted was a baby who did not need tubes to survive. I had to take aspirin and calcium supplements from conception, and although these are not proven to combat pre-eclampsia, it made us feel we were doing something to prevent it.

We did not tell anyone but a few special people, my family and my husband's father included, till I was 20 or so weeks pregnant, at which time we also told them that we were expecting a daughter, and announced her name. I desperately wanted to name her after my sister, so we used my sister's name as her middle name. For us it had been very important to find out the sex, and to name the baby and give her a new identity as soon as possible. That way she would be with us for as long as possible, if she were to die too. And people were going to be made to acknowledge her! We were both relieved to discover she was a girl. I was sure this would mean I would not hallucinate that I was pregnant with our son again (there were some moments in the pregnancy when I felt as though I was, especially when I began to feel her moving). Although part of me would love a boy so that some day I might know what our son would have been like, I am still scared of having another.

From around 24 weeks the pregnancy became very different from the first. Whereas the first had been carefree and joyous, this time I had to rest and have frequent foetal and placental monitoring (each of which were in themselves roller-coaster events), and of course we began to feel as if we were on the edge of a cliff. If she were born early she would be susceptible to the problems of prematurity, but if we left it too late she could be injured by sudden-onset pre-eclampsia.

As time went on and the results of the foetal and placental monitoring continued to return normal results, it became evident she would not have to be born prematurely. We couldn't believe our luck. In the end it was decided that she would be born at 37 weeks if all continued to go well. I probably felt better than anyone else during the later weeks: my husband was terribly fraught, and my mother and sister, despite being 20,000 km away, were deeply involved (my mother was the only member of my family to see our son, but

only in the funeral parlour). We were dreading the c-section and could only think of the last time when everything had gone wrong.

The last few days were a dreadful strain – we ended up having the caesarian section a few days early as we just couldn't take the strain any more. My husband was beside himself during the operation and wept openly with anxiety and stress. Suddenly she was there, safe and sound, with no signs of pre-eclampsia. I shall never forget the paediatrician telling me that the amniotic fluid was clear, and then hearing Madam scream for the first time! Instantly she reminded us of our darling son – this shocked us, and still does. Some people have tried to tell us there's no resemblance, in a vain attempt to make us feel better! They don't seem to realise we love the way they look alike. I would find comfort in any similarity, for example, if they had shared their birthdays.

Our main emotion in the first few days was relief, not happiness – I think it took a while for us to accept that she had safely arrived and to enjoy her. I also felt relief that we had at least one living child (as opposed to being childless for the rest of our lives). Every time she got us up in the night, we felt no frustration or dismay, simply happiness and relief that she was able to do so! I had expressed milk for our son when he was in the Neonatal Unit, so breastfeeding was a bittersweet time as well (and still is). When the baby blues hit in, it was all focussed on our son. Almost no-one except my husband and my sister really understood this. Much of this came from the fact that our daughter was innocently doing things (crying, moving, etc.) which our son had not been able to do.

Of course everyone was delighted for us (some were evidently relieved that we were now 'better'. Some friends who had avoided us when our son died got back in contact when they heard we had had our daughter safely. We have not met up with them). Even some of those closest to us did not understand that although our daughter was utterly delightful and deeply loved, she was no replacement for our first child. I still can't look at children his age without feeling sick.

Immediately after our daughter was born, I could not face attending the local mothers' group, but I did recently join the next intake of mums, and find myself enjoying the sessions and making friends. We want our daughter's childhood to be as normal as possible, and we would love to have more children, hopefully as soon as possible. Each pregnancy will be assumed to be high risk and monitored in the same way, and the delivery planned, but we hope we have hit on a winning formula.

Kate S's story, mother of Hamish who died suddenly and unexpectedly from whooping cough on 23/10/00

Because Hamish was our only child, we noticed as soon as we came home from the hospital how cold and empty our house seemed without him. For Cayle, the decision to have another baby happened in the first 24 hours, I was more reluctant, thinking that we would fall straight away and people would think that we were "moving on" too quickly. But it was in the first week that we decided all we wanted was a little baby back in our arms.

The best thing we did after this decision was to buy a puppy for me to give all my maternal feelings to, until we were parents again, knowing that this would be 10 months away at the least. We ended up with a very loved and spoiled dog (Oscar), but I will be grateful to him forever for pulling me out of some of the worst slumps in my life. He gave me something to get up for because he needed to be taken care of.

As it turned out, it took six months for us to fall pregnant, and every disappointing month I focused on it happening "the next time". But in hindsight, we really needed this time to come to terms with our loss, and I don't think I could have coped with a pregnancy in this time, it would have been too high stress for myself and the baby. But I don't regret making the decision to try straight away, as the hope of falling pregnant gave us a goal to focus on and took us from month to month.

During my pregnancy I could not relax until the 32 week mark, as I felt that I would miscarry before this time, and after 32 weeks the baby has a good

chance of survival if born preemie. At this moment I am 2 days off my due date, and have many fears concerning a safe delivery. I am so aware of how many things can go wrong and now even though Hamish died of an illness, I am afraid of my baby being stillborn, and if she survives this fear, then she may die of SIDS. One thing is certain, and that is I find it very hard to see my baby reach past three months of age. I have bought larger clothes for next summer to be a little bit optimistic, but still cannot see her getting the chance to wear them.

We found out the sex of our baby after having an amnio, which determined she was a girl. I was fleetingly disappointed, Cayle much more so, all he wanted was his little man back. I was relieved after a short time, because having a girl felt like a fresh start with not so many comparisons to her brother. It also meant that the decision not to use Hamish's clothes on her was much easier. We went out and bought a whole new lot of pink clothes, and redecorated Hamish's room in feminine style, so that it was barely recognisable. We kept all the same furniture.

When trying to conceive, the thought that I might be due around Hamish's birthday in August, or his anniversary in October, was always in the back of my mind, so on these particular months for conception, we probably didn't "try" as hard, but did not give up altogether because at this stage I was set on the task at hand to fall pregnant. Fortunately it did not happen and the baby is due in January, which had no meaning for us concerning Hamish.

We decided to go back to the same hospital to have our baby, because they looked after me so well when I stayed there before Hamish's birth. When he was sick they did everything possible to take care of him, and we could not fault them for anything, so I know that my baby will be in good hands.

Postscript

Our subsequent baby, a beautiful little girl Brielle, was born 15 months after Hamish passed away. She was a week overdue and because I was so stressed out, my doctor decided to induce me, and she was born a quick two and a half hours later. I surprised myself and others around me, at how calm and relaxed I was straight after the birth holding my new baby in my arms. The fears I felt for Brielle's safety all through the pregnancy just melted away at this point. Somehow I knew she would be our saviour and would never leave us.

I decided not to use a sleeping monitor, as I knew they were not lifesaving devices, and would probably cause us less sleep. She slept in her own room from the night she came home, and when I put her to bed every night, I slept soundly, knowing that I had followed all the 'safe sleeping' advice, and so I had done everything I could to make sure she would survive each night.

It was hard becoming attached to her in the first month. Both Cayle and I loved her deeply, but at the same time we were afraid of her. After that initial adjustment period, we allowed ourselves to become closer to her every day, and now she is the centre of our universe. At 14 months of age, Brielle is certainly a wild child, and she is amazing us all the time with the new things she is learning every day. I am so thankful that we did decide to have another child so soon after we lost Hamish, because she has not replaced him in any way, but she has helped to heal our hearts, and to let us trust again. We are now 27 weeks pregnant with our third baby, and it has certainly been a much more relaxed and different journey than Brielle's pregnancy. I am much more confident with this pregnancy, now that Brielle proved me wrong and lived past her first year. We still think of Hamish every day, and his birthdays and anniversaries are especially hard, but having other children to focus on and give all your love to, makes each day much easier to breathe.

Kate D's story, mother of Lily who died of SIDS on 26.11.00

Family at that time:

Mum – Kate

Dad – Simon

D'Arcy – 5 years old

Hamish – 4 years old

Amelia – 3 years old

Lily – died at 6 weeks

I was on drugs for epilepsy during all my pregnancies. When I went on to a new drug to manage my epilepsy I was told I had to consider having no more children. I persuaded my neurologist that I should be allowed to have another baby and to breast-feed her. I feel guilty now about pushing for that. However there is no evidence/proof that Lily's death was related to the drug. But as a mum there is incredible guilt that goes with losing a baby regardless, so if there is an extra reason for the guilt it is not a help.

I feel that it is a waste feeling so guilty. I have got better at coping with it – it is very destructive to feel that way. It is like a huge bridge that I couldn't climb over. The guilt fuels the grief.

Lily, our fourth child, was born on 12th October 2000. She lived for 6 weeks 2 days and died on 26th November. She was loved to the point of excluding everyone else – I was very selfish in my love for her. I didn't exclude my other children, but I did exclude my husband. I knew she was the last one (because of difficulties with being pregnant) – so she was cherished by all of us – my husband, my kids and myself.

The night before she died, Simon was going out. I was starting to feel an incredible lack of freedom owing to our four young children and resented his going. I took Lily into my bed and played with her for four hours. I thought 'I don't care you are out, I've got the most beautiful baby in the world in my bed.' Simon came home a bit later. Lily stayed with us and we went to sleep.

I was relaxing and dozing after feeding her about 6 o'clock in the morning when the kids came barging in to give her a kiss. I said "Can't you for once just let her wake up normally. You're always giving her kisses and ruining her sleep." Then we realised that she was in trouble and not breathing. I sat up. I looked at her and saw she had haemorrhaged all over the place.

I screamed at the kids to get out of the room. I said to Simon to resuscitate her and I would call an ambulance.

The ambulance came and Simon carried her out to them. He sat like a shattered man on the kerb whilst they tried to revive her. He didn't want to go to the hospital with her in the ambulance – he knew. He saw more than I did.

All this is in your head when you think about having another baby.

We didn't start thinking about having another baby for a while – probably about 3 or 4 months later. I felt so cheated out of my motherhood – even though I had these other beautiful children. I felt so cheated: "empty arms" describes it.

I started to talk to Simon about it; I had had to push for him to agree to having Lily. So this time it didn't take too much convincing. He was devastated. Very few people asked how Simon was doing – they asked how I was doing. We both feel that this is very unjust. He was so pleased that he had got to know Lily. He was freelancing at the time she was born, and he had the time to get to know, love and grow attached to her. I don't think he needed a baby like I needed a baby. The main issue for him was that something might happen again.

I was really scared too. I didn't really talk to anyone about it. I knew my family were so worried about me – not wanting me to be hurt again. They said it was too soon. And yes, it was too soon. But then there isn't a good time. It would always be too soon. I wasn't prepared for the fact that being pregnant would open up my grief and issues that hadn't even been realised.

Just a short time before I found I was pregnant, Simon decided “No – we have three beautiful children and we will give everything to them.” I felt that this was a valid decision and I agreed with him. I got a job and decided our life would take a different turn by not having another child. I would start focussing more on our three living children.

I found out the weekend before I started work that I was pregnant. I told Simon, but I couldn't tell anyone for 15 weeks because I was having so much difficulty in dealing with it. I was so worried about everyone's reaction – that they would think we were replacing Lily. I knew my family would forgive and understand me. I was so scared for us, for our kids and our families. I didn't want SIDS to strike again. It wasn't supposed to happen in the first place. These things are supposed to happen to other people – not to us. I didn't want to go through another sickly pregnancy again. I wanted Lily back.

After I started telling people, their kind, generous reactions helped me to come to terms with this as a good thing. Although in life sometimes good things are hard.

When I told Simon, he was very matter of fact. “Well it's done now.” I know he has had a hard time coping with his fears like I have – and still do. But he was lovely in his acceptance.

We told the kids at about 16 weeks. They have been so excited. At first they thought I was having Lily again – that took a lot of explaining. The children have fears. D'Arcy has fears. Last week Hamish said he was looking forward to going to the zoo after his birthday. He said “Will we do it after this baby dies?” I said “Hamish, not all babies die.” Then he talked about Lily.

I've been overwhelmed by our children since Lily's death. I never would have believed such young children could grieve so strongly and perceive future situations with such maturity.

Lily's death caused grief to my five siblings and Simon's four siblings. We have wonderful memories of Lily, but we can't think of them without crying: there is so much sadness because of what we have missed. I know this baby will bring so much happiness back into our family. Even now it is not always a sad house.

The big reason for having another pregnancy was that we didn't want to always live in sadness. The amazing hole left by Lily's death will not close, but a new baby will bring a lot of pleasure not only to me, but to Simon and the kids.

Postscript

Lily's youngest brother Finn was born fourteen months after Lily's death. He is a beautiful redhead. Finn's delivery was short and uneventful, I just wanted him out. I had wanted a girl really badly however when he was given to me all wrapped up and the doctor asked me to look and see what sex he was, I remember just cuddling this beautiful new life and saying that I didn't care. This baby had arrived alive and well and that was all that mattered.

The end of my pregnancy was not so good. I had three scares. At 32 weeks I was hurried to Melbourne by ambulance causing both Simon and myself great panic. However they managed to stop these impending labours.

Once the time came for Finn to be induced Simon and I felt great relief as we had been through enough emotional turmoil and worry. I kept asking the doctor if he would die and he said "No, he will grow to be an old man". How generous! He could never guarantee this but he knew at the time, I needed to hear these words.

We both knew that the first six weeks of Finn's life would be difficult. We had all these reminders with all our children looking very much alike. We also had the worry for no other reason than that the unthinkable had happened

before. If he didn't die of SIDS he could die of numerous other things which we were fairly oblivious to with our other children. Simon is incredibly protective of Finn and I think will always be. I was a mess a lot of the time and could feel myself holding back from loving him to try to protect myself. Simon coped by just being overprotective.

Logically I realise that a child can die from SIDS at any time in their first two years or more. However on the evening of Finn's life when he was six weeks and one day old I was petrified. He was a little bit sniffly from a cold as Lily had been that night in her life and I was terrified. I ended up sitting upright with Finn at my chest so he could breathe more easily. When he awoke upright the next morning I was exhilarated that he was still with us. It was only then that I realised how much I loved him and how right our decision was to have him.

The kids have been delighted with Finn. Having Finn for them has been really healing and so much fun. Amelia I know, cannot remember much about Lily's life, but she will never forget the sadness of her passing, I am sure.

Hamish and D'Arcy both remember. D'Arcy the other day said with so much passion "When we die we will go up to heaven to see our beautiful Lily Grace and we won't have to cry anymore." Hamish asked me, "Did you know, Mum, that some families have babies that don't die?" He is starting to realise that we are an exception to the rule rather than "the norm".

For me, Finn has brought me so much love that only comes with a new baby. The pain of my pregnancy was all worth it as we have a beautiful boy to love and cherish. I now feel as complete as I ever will. I will always want my five babies in my arms but know that I will only ever have my fourth child in my heart.

Acknowledgements

SIDS and Kids would like to extend its gratitude and appreciation to Carol Quayle and Anne Giljohann of SIDS and Kids Victoria, Anne Dawson of SIDS and Kids New South Wales and to all the people who contributed to this publication. Thanks also to Dorothy Ford of SIDS and Kids, and to Jo Durst for editing. Without their help this booklet would not have been possible.

We would like to thank the following parents for their quotes, thoughts and contributions:

Jo Durst, Barb Turner, Jo Wade, Wendy Walsh, Wendy Claridge, Angela Dabb, Maria Kelly, Dianne Campbell, Angela Uhrhane, Jenny Donaldson, Mary Storey, Mandy Marsh, Carol Quayle, Helen Dawson, Cas O'Neill, Sue-Ellen Robertson, Sue Graves, Kim Hill, Ian Johnson, Carin Vernies, Sue Rojas, Anne Dawson, Sally Stewart-Hunter, Glen Thompson, Steve Warnes, Sharon Bassham, Antoinette McLeod, Jennie Adams, Lisa – Qld, Kaye Freeman, Kathleen Zarubin, Michelle Dastlik, Susan Sullivan, Jenny Johnson, Kim Squires, Kaarene Fitzgerald, Deidre Bohan, Kate Dunn, Keren Ludski, Megan Sarson-Lawrence, Kaylene and Bill Vlasveld, Liz Green, Petra den Hartog, Kate Stuart, Suzette Donald, Carol Matthey, Anabel Silva, Carinna Johnstone, Amy O'Connor, Heather Schwarz, Josie Frisina, Dominique Elliott, Jeff Elliott, Kim Kneale, Helen How, Nadine McDonald, Simone Zmood, Alexandra Cooper, Brenda Rutherford, Melanie Walden-Mills, Kate Foley, Laura Warner, and Vanessa Gorman and Michael Shaw from the ABC TV documentary, Regarding Raphael.

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SIDS and Kids Organisations

For more information, further reading materials or if you would like to talk to someone please contact the SIDS and Kids office in your area on 1300 308 307 or visit the SIDS and Kids website on www.sidsandkids.org



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Thanks to George Patterson Bates for creative design.
Reprinted December 2003.



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