

A booklet for bereaved parents whose young child has died suddenly and unexpectedly



guiding light

Sudden Unexpected Death in Childhood

**red
nose**
Grief and Loss



Foreword

When my daughter died in April 1996, aged nine months, I felt entangled in a cruel web of emotions, sometimes spiralling out of control, sometimes colliding, sometimes overwhelmingly lost, suspended in a place where I did not want to be. I did not know whether I could find my way free from the chaos of grief. I felt spiritually, emotionally and physically bruised and battered. We had not planned for the death when we decided to make our family. I did not know what processes to expect, if we had any choices, or if we would in fact survive after the nightmare began. Although my family and friends surrounded us, I wanted to know why, I wanted to try and understand and find answers and, most of all, I wanted to know where it would lead me in the future.

One of the most helpful things for me was to begin to listen to the experience of others. I wanted more personal stories and I wanted to know that I was not alone or heading for madness or mental instability! Everyone's story is different but so much of what we need to 'go through' is similar.

This booklet grew out of the experiences and needs of parents whose young child has died suddenly and unexpectedly. This book has been developed and thoughtfully written by our wonderful grief counsellor, Denise Same, with support from her colleagues.

The pages guide us through the trajectory of grief, giving practical advice, offering choices and sharing the wisdom of those who have walked this path before us. The words are both comforting and enabling, a useful and gentle guide to the future. I would most strongly recommend this booklet to you.

Jill Green

General Manager Research Advocacy and Change and mother of Molly Rose.

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Introduction

The death of a child is like no other death – it has been described as the ‘ultimate loss’, a loss of hopes and dreams, a loss of part of oneself as a parent, the loss of a role and purpose in society, a loss of a future with your child. This grief is not only painful, but profoundly disorienting – children are not supposed to die.

The death of your child has the potential to create lifelong changes in you as a person, as a couple, and in your family and your networks. Such a death usually causes immense personal distress and interferes with your normal every day functioning, your family togetherness and broader social relationships. You will be forever changed, as will your key relationships.

As bereaved parents, you must deal with the contradictory burden of wanting to be free of this overwhelming pain and yet needing it as a reminder of the child who died. Through the following pages, we are shown, through the words of bereaved parents, that there is a pathway to survival and living once again.

This booklet shares the thoughts and feelings of parents who have experienced the sudden and unexpected death of their baby or young child. The parents who contributed to this booklet generously and courageously shared their reflections, insights, thoughts and feelings that followed the death of their children. We learn what continues to guide and support them on their journey of grief. Their stories are offered in the hope that no family feels they are grieving alone.

“Over time I was able to smile again. But when she died, I felt life was not worth living.”



The sudden and unexpected death of a child

The impact of a sudden and unexpected death of a child presents unique grieving factors and raises painful psychological issues for the parents and family, as well as those who support them. Parents must deal with a child's death that is sudden and unexpected; a death so sudden that it leaves no time for preparation or goodbyes.

“ If I had known she was so sick, I would have insisted she stay in hospital. But I did not know.”

Any infant or early childhood death forces us to think about our own vulnerability, but a sudden and unexpected death can also bring with it an absence of answers and a frightening loss of control. Most parents feel that nothing in life is predictable, that everything has been turned upside down. Obtaining reliable information and having access to professional support can be significant at this time.

“ It was so hard to trust that life would ever be OK again.”

“ We both felt so much pain I thought it would kill us. When I realised that it wasn't going to, I prayed that it would.”

“ We were together and shared the grief, but I saw stuff in myself and in Paul that I didn't recognise. We couldn't recognise each other, let alone ourselves. Our reactions were so confronting. We wanted to be there for each other but couldn't even be there for ourselves.”

The nightmare begins

For many parents, the period following the death of a child does indeed feel like a nightmare, with the desperate need to wake up and find everything is OK again.

“Why am I bothering with life? How can I go on with my life when my son is dead? A child is so much part of your future that when that child has gone, you are not the same.”

“Nobody knows what they can handle until they have to. If someone had told me that my child was going to die, and that I was going to survive it, I would have said, ‘You are absolutely crazy. I could never handle that.’”

When a family member, carer or bystander rings 000, both local police and ambulance are notified, even if only one service has been requested by the caller.

Police investigation

When a child dies suddenly or unexpectedly, regardless of age, the law requires that the police attend and report to a coroner. The coroner then decides whether the child needs to be brought directly to the coroner’s or not. The protocols of the Emergency Services personnel and also the coronial process may vary in different States and Territories.

We refer you to the booklet: “The Coroner’s Process - Information for Family and Friends” in your area.

“I remember that night when the police came. We roughly had three lots of police interview us. The first lot were uniformed. They arrived fairly quickly after they had pronounced Sian gone.”



“ I thought they believed that I had murdered my child. And I just sat there ... there was a young guy, who we called the ‘tea boy’, who I thought was straight out of the academy, he went off to make the tea! But the girl, and I still remember her name - it was Alexa - she did nothing, and I mean nothing, to make me feel not guilty. I sat there and thought: How do I make her believe me that I was not...I was on my own when Sian died, and it made me think it was my word against everyone else’s. How do I tell her...I just kept saying over and over and over again ‘I tried, I tried so hard to save her.’”

“ I may have felt less guilty if they had assured me it was just procedure. I had no idea that the police would come to our house to photograph everything. And so when they came in and said the police were here to see us, I thought like ‘Oh My God, they are going to lock me up!’ I honestly thought they are going to take me away tonight and lock me up because they think this was my fault. And that is scary stuff.”

“ Another two arrived in plain clothes and this police woman was a much nicer lady. She explained that she had some questions that she needed to ask me and I have since found out from a friend of mine, who is in the police force, that it has all to do with SIDS. They have a questionnaire. She went through a lot of questions and said, ‘I am sorry I have to ask them.’ She was very apologetic and said it was procedure.”

“ We were told she would have to be taken to the Children’s Hospital. Rob and I discussed carefully, lovingly, what she should wear and decided upon her pink and blue gypsy dress. We dressed her with all the care and reverence we had been unconsciously storing up for her first day of school or maybe her wedding day, while all the while fighting the thought, ‘None of this matters: she’s dead.’”

(please note: protocols vary from state to state.)

Once the police have completed their investigation, some Australian States offer the option for parents to escort their child to a hospital to spend time with him/her in a supportive setting. If you are able to do this and make this choice, you may wish to carry your child from your home to the ambulance and to nurse him/her during the journey to the hospital.

“ At the hospital, I remember looking from Rob, to my father, to the Doctor, to a friend who had joined us: looking for some explanation of the horror that had just occurred. I also remember the beginning of a feeling that continues to this day, a feeling of having my heart wrenched out of my chest.”

During the time spent with your baby/young child, you may choose to take photographs, collect a lock of your baby's hair or spend precious time talking to your baby/young child, saying things that would otherwise have been left unsaid. You may prefer to just look and hold and create memories this way. Other children may also be encouraged to spend time with their brother/sister.

In Australia, the Emergency Responders will do their best to make this possible, either at home or at hospital.

“ It would have been helpful to be told: here are things you need to think about. You need to think, in your own time, about gathering photos together, in fact, have a checklist where you can say: ‘Cool, I have to do that.’”

“ I hadn't realised the significance of being asked by the nurse, ‘Would you like a lock of your little girl's hair?’ So many years down the track and I still touch the locket around my neck holding a piece of her hair. I remember and hold her close to my heart. I need that. It is all I have.”

Some parents may request to stay at home or at the scene with the child until the arrival of the Coroner's contract Funeral Director. It is possible for you to spend time with your baby/young child at these places. Sometimes, where a post-mortem is legally required, you may not be able to touch and hold your baby/ young child until after this



has been completed.

“ A booklet needs to be given to parents at the hospital when they leave. You need to be armed with as much knowledge going home as possible. We walked out of there with nothing. Even with the Coroner’s booklet, we were still clueless. It needs to be in a pack of some sort where they say to you: ‘Don’t look at it now, but if you have any questions they are going to be answered in this book.’”

It is important to be able to ask questions. The Coroners Court’s Family and Community Support Service in Victoria, for example, offers assistance and advice, and can be called at any time. Check your own State’s availability.

“ I didn’t know what to ask. I felt stunned. It was invaluable being able to talk to a counsellor who spoke so openly and encouraged me to think of questions I wanted answered now. It is important to look back and have no regrets. You need someone to guide you.”

Post-mortem examination

What is an autopsy?

This is sometimes called a post-mortem and is a type of medical procedure performed by a pathologist. The pathologist will carry out an external and internal examination of the body, treating the body with respect at all times.

It is often difficult to grasp that decisions about your child's body must be made so soon after death. Having to comprehend and discuss a post-mortem examination of your child's body can be too painful to endure. At the same time, be aware that a post-mortem may provide vital information that will help you come to understand the reasons for your baby/young child's death.

“ I wanted to understand why my baby died and, at the same time, I didn't want anyone to touch her body.”

“ Maybe at the hospital there should be someone that you can call who can say: 'I know that this probably makes no sense to you now and you are probably not even listening to me, but here is something that you need to read when you get home and have time, or give it to a loved one to read to understand what is going to happen next so they can explain it to you.'”

During a post-mortem, the baby/young child's body is examined to reveal a possible cause of death. This examination very often includes a surgical procedure, which is performed by a pathologist, where incisions are made in the baby's body to enable examination of internal organs. Following the examination, the incisions are stitched. It is important to be reassured that an autopsy is an operation carried out by a pathologist with the same care as an operation on a living person.

You may have concerns about how your child's body will look after the autopsy. Medical and nursing staff will be able to accurately



describe the position of the incisions on your child's body. You may request to see your child dressed, so that the incisions are covered, or you may feel it is important to see what has happened. That decision is entirely up to you. Be reassured that the people at the Coronial Services Centres who look after your child will do so with great care and respect.

After the autopsy, you are able to see, touch and hold your baby/ young child. For many families, touching one's child is an important part of the grieving process, and the court will work with families to facilitate this.

“ Going in to the Coroner's and seeing her the day after she died wasn't as bad as I had thought. I had visions, from TV, of Sian being laid on a slab. She WAS cold, she was freezing and she was on ice and she still had the tube in her little mouth. The guy warned us about that. He stayed, he wasn't allowed to go. That was another thing, too, you didn't actually have any private time.”

“ We felt like we had to hurry because he was standing there, it was Mother's Day, and all I wanted to do was just sit and be with my daughter. We were allowed to touch her but she was just so cold. When we went into the Coroner's the next day, they were very good. I took in pyjamas and her Wiggles blanket and I said to them, 'Please can you dress her in these and wrap her in this before the Funeral Director picks her up. When you are finished doing what you are doing, can you please dress her?' and they did.”

Who decides on an autopsy?

The coroner makes the decision regarding whether to conduct an autopsy after considering the wishes of the senior next of kin and any information provided by police, pathologist or other scientist.

The autopsy may be undertaken at a Coronial Services Centre or a regional hospital. Babies and young children are returned to their families or the nominated funeral director, often within 48 hours. The Coroner has to establish the cause of death and to do this, he/

she must find out the circumstances surrounding the death so as to distinguish between natural and unnatural deaths, accidental and non-accidental deaths. It is the Coroner's duty to investigate all sudden and unexplained deaths. The fact that a post-mortem examination has been done and the Coroner has looked into each death is a safeguard against any possible doubt or criticism of the parents, the family, or whoever was looking after the child at the time. Understandably, this can be a very distressing time. You might find it valuable to spend time discussing the examination with your doctor or hospital social worker. They can also provide information and brochures about post-mortem.

“ In conversations at the Coroner's, we would always use speaker phone and have Jacqui's sister sit there and take notes. She would write down specific terms so if we wanted to back track on anything, we could Google a term to learn more about it.”

Objecting to an autopsy

Anyone can write a letter to the Coroner, within 48 hours of the death, to object to an autopsy being performed. There may be cultural, religious or other reasons for objecting.

“ We were asked if we wanted to have an autopsy and we said 'No'. Because our brain didn't really work, and we were shocked, the only thing we could think of was, we don't want X's body to be cut.”

“ However, after a while it became a big issue to my wife. She always thinks that she wants to know exactly what happened. It is bothering her all the time up till now. I don't know when this wondering will be ending.”

“ If you don't know why your baby died, I don't reckon you can go through life without knowing.”



“ We absolutely wanted an autopsy. We went into the coroner’s and saw her the next day. We knew we could do that because they told us at the hospital that we could.”

Waiting for results

A Funeral Director can be contacted as soon as a child has died, without waiting for the Coroner to release the child after the autopsy. As soon as any medical procedures are completed, the Coroner can authorise the release of the child to the chosen Funeral Director or to the parents, if so desired.

It may take many months for the full post- mortem results to be released, and this can often complicate the grief process. One parent might blame the other or themselves in the period before getting the full picture. It can be helpful to ask a professional to explain the post-mortem results, as they are often couched in scientific and medical language. This is also a time when children can find it difficult to understand what is happening. It is important to talk openly and honestly to them.

It can be helpful at this time to liaise with a Funeral Director, to begin the process of thinking and discussing how you may say goodbye to your baby/child.

Organ retention

Occasionally, as part of the autopsy, it is necessary to retain whole organs such as the brain or heart, or larger portions of tissue for medical tests to help further investigate a death. This subject can be quite a challenge to a parent’s belief system. For example, some parents cannot envisage their child being at peace if they are not bodily whole, while others may view the body as a physical container, serving a purpose only in life.

Agencies such as Red Nose Grief and Loss, Sands and The Compassionate Friends are sources of valuable support for families confronting the issue of organ retention.

“ Sam’s brain was being studied for a long time by the Coroner. The funeral director wanted permission to take possession of his body and to combine him with his brain when the study was finished but we chose to keep him with the Coroner so as not to separate him even more than necessary. This also meant that his body wasn’t with us at the funeral. Some people thought this was strange but I didn’t like the idea of his body being there incomplete without his brain.”

Tissue donation

The court can facilitate contact with the Donor Tissue Bank in your state if you would like to consider consenting to tissue donation, for example, heart valves, skin, bone and corneas. Organ donation usually takes place in a hospital.

“ We had questions at one stage about whether we could donate her organs or some tissue, and we really wanted that to happen, but because of what she had, she couldn’t donate anything, which was upsetting to us.”

“ Although our little girl had died and grief consumed our hearts, I remember my partner and I looking at each other and thinking that we would never want any other parents to go through what we were feeling. If we could donate to help another child, we would, even though this was confronting to think about.”



After the autopsy

Hospital, Coronial Services and funeral services staff understand your need to spend time with your child.

They understand that it can be very important to you to see and hold your child and to involve brothers and sisters and other family members. Spending time with your child, prior to the funeral, might take place at the Funeral Home, at your house or at a place of your choice. Ask a Funeral Director to make the necessary arrangements.

“ We had the chance to spend some time with Sam at the funeral place before the cremation. We both brought a letter to him to cremate with him and a lock of our own hair to place in each hand. He also had his special toy with him in the end.”

Don't forget, you have choices every step of the way

“ They said we could see her when they took her back to the Funeral Parlour.”

“ When S got back to the Funeral Parlour she was dressed in her pyjamas. When we undressed her, to change her into her school uniform, that was a little bit of a shock too, seeing her scars. But they did it well...if you can do an autopsy well.”

“ The children held him at the funeral parlour – they all said this was a very special, important time.”

You might like to use this time with your child to take photographs and create other memories. You may also wish to give your other children, family and friends the opportunity to spend some time with your baby or young child before the funeral or memorial service.

“ My regret is that the Funeral Director asked us if we wanted to take Sian home before the funeral and we said 'No', and that is a huge regret.....a huge, huge regret that we didn't

bring her home for a while and put her in her bed in her room. I said 'no' because I thought if we bring her home I won't want to give her back again."

“ It's a cultural thing, like a wake, bringing the person back to the house. That's never really been part of anything I would do.”

“ We really wanted to see her again and we did get the chance to get a private moment with her before she was cremated. Thankfully we did that. It's very, very important.”

“ We were able to have Iris home in the days leading up to her farewell. Having her home brought a strange sense of peace to us all, and we were each able to say goodbye in the way we needed to. We filled her coffin with gifts for her journey: her favourite bear, some crayons and paper, her favourite CD, photos, letters and her birthday present.”

“ I remember going to the florist and picking out the flowers for Sian's casket for the church.....As you walk into the florist, there is a computer screen and it plays photos of weddings and I remember looking at it and thinking (cries) 'I am never going to be able to stand here with Sian and talk about her wedding flowers', so I was determined that she would have the best! They were amazing, they looked beautiful. And (laughs) they weren't cheap! I remember Mark saying that to me when I told him how much, but, you know what, these are Sian's flowers. We will never pay for her wedding flowers, this is it, this is her very special occasion and I want it to be the best.”



Choosing helpers

There are different ways to organise a funeral. Some families want to do all the organising themselves, whilst others look to the Funeral Director to guide and support them. Finding someone who will spend time getting to know your needs and wishes and help you arrange the service your way can be helpful.

“ We did not do it on our own, we had our parents, Mum and Dad were there then.”

“ My Dad was there.”

“ And my sisters were there.”

“ When they arrived and we all sat down around the dining table, Jacqui’s sisters and my Dad, the Funeral Director said: ‘Right, can everyone else go away please?’ We were shocked and thought, that’s really rude, (laughs) but she said ‘I have done this for a reason. I will bring the family members in afterwards but I just want to channel in on you two and hear about your memories of Bethany’, and it actually turned out really good. Maybe she had learnt that skill over the years. There was stuff coming from everywhere and it was really confronting, but after an hour or so you sort of realise it was important.”

“ I was dreading having that sit-down chat about things, like choosing a casket ...it felt like being in a play.”

“ My cousin, Jennie, was there but she was there purely to take notes and see if she had to do things for the funeral - she did not interfere at all, she just sat in the corner and took notes. That was a really good strategy, because then I could say to her

later: 'Hey Jennie, what did Tim say about such and such?' and she had it all written down."

“ There is a lot to organise. And I remember saying at the time 'How do people manage to organise a funeral in two or three days?' I am glad we had that time. We had amazing help. My cousin, who is an executive at an IT firm, just came in. She respected everything we wanted - she rang the printers, she typed everything up, she organised and sent us proofs. I knew what I wanted for the Mass because I have taught in the Catholic system and I have planned plenty of Masses, but Jennie did the footwork in terms of that. That was a huge help.”



Arranging your child's funeral

There are so many questions to ask and questions you may not think to ask. Should we bury or cremate? Should we involve our other children? What sort of funeral? Who should attend? How much should we do? This period can be totally overwhelming with so many choices to make.

Red Nose Grief and Loss has a booklet called "Choices in Arranging a Child's Funeral" which is full of information and ideas.

The funeral is the last physical act of caring for your child. It is a time, amid profound grief, when you can acknowledge your child and the meaning your child's life holds for you and your family. After a child has died, you may feel shocked, angry, upset, numb and confused. It can be hard to take in what has happened, what it means to you and your family and what has to be organised. The most important thing is to *take your time – don't rush*. Do what you feel is best for you and your family. The choices you make now for your child are important now and in the future.

“ We decided to do whatever special things for her we wanted. We wanted no regrets when the funeral was over.”

“ What we really needed was to take care of our baby one last time.”

“ We wanted to plan her funeral as thoughtfully as we had planned her arrival. The sacredness and care with which we approached both events was similar, but there was no joy, no sense of anticipation.”

Arrangements for children and babies may be quite different from the way adult funerals are conducted. There are few legal requirements in arranging a child's funeral, although your religion and culture may guide you in your choices. Take your time and do exactly what you want, so that there are no regrets.

“ We had a kind of delay really with the Coroner. It took a while, eleven days, between Sian dying and her funeral. I think that was a good thing to help us process this a little bit. It gave us time to think about what we wanted to do, rather than being rushed. That really helped us to then celebrate her the way we wanted.”

“ Arranging our child's funeral ourselves gave us something to do during those dreadful days: it gave us a sense of purpose.”

“ The three days between his death and the funeral felt like an awfully long time, but this timing was right for us.”



Other children in the family

There are lots of ways in which you can include children in the arrangements for the funeral. Being involved helps both you and them to adjust to your child's death.

“ Involving our daughter in the funeral is something that is not our right to tell her 'No'. It is her right to have that memory, because then if she grows up and says 'I don't remember Beth's funeral', it was not our decision.”

If children are going to come to the funeral, it will be helpful to prepare them for what they might see and hear, before, during and after the funeral. For example, you can help them to understand that the people at the funeral will express their sadness in different ways and that some of them may be crying and upset.

If you have an open casket or if you choose to view the body before the funeral, prepare your children for what they will see, for example, the body will be cold and still. Be prepared for the questions your children may ask. Red Nose Grief and Loss can help you prepare to answer questions.

“ Charlotte probably thought it was Beth's engagement party. We said it was her funeral but we had just been to an engagement party so it was on her mind. It was Beth's party all the same. Her engagement party, that'll do!”

“ Dane was only 18 months old but he was at her funeral and we never questioned him not being there. He was there and he was up the back running around with other people, but he was there.”

“ We made decisions on what we thought was best for the children, but now wished we had involved them more.”

“ We explained everything to our children, J (4) and D (3). They drew pictures and put them into the casket.”

“ I now know that Mum and Dad were trying to protect me, but I wish I had been able to say goodbye to my little sister my way. I wished I had been able to give her a last kiss and say I loved her.”



To bury or cremate

This, in all likelihood, will determine the final resting place for your child. If you choose to bury your child, the burial must take place in an approved burial ground/cemetery. If you choose to cremate your child's body, there are no restrictions on what to do with the ashes. You might decide to bury the ashes or to scatter them. Or you may want to keep them at home with you.

“ We still have the box of ashes on the bookshelf at home. We haven't got around to scattering them yet.”

“ We chose a country cemetery, where we found a plot which we thought was just right. My husband lovingly made a unique headstone which he designed with koalas and stars on it.”

“ There are decisions I regret, like now I think we should not have rushed into burying her. They can care for her ashes for up to twelve months at the cemetery. I think the whole decision was rushed. Time is really important. So now I feel like she should come home whereas, before, Luke wanted her home.”

“ I wanted to have her in the house.”

“ We were moving and I did not want to bring her ashes home to the old house where there were happy memories of her life and of her being alive. We were moving and I did not want anything to happen to her while we were moving. And so now we have been in the house for a year and I feel like it's our home now and she should be there.”

“ I, however, couldn't bear to move her from her resting place. To me the cemetery is her little home now.”

“ He respected my choice then (to bury her) and I have to respect his now, and leave her there.”

“ I’ve got a concern about what will happen to Sian after Mark and I have gone. Sian’s at home now but...we wonder about who will look after her when we are no longer here. To me, that’s also an issue.”

“ Being in the cemetery means we don’t have to worry about what happens to us, she’s always going to be there.”



Grief and feelings of loss

In the beginning you may feel so shocked that your body and mind cannot even begin to comprehend all that has been lost. Your investment in such a precious life is immense and deep-rooted.

Other than stating that it is perfectly normal to feel depressed after a sudden and unexpected death, there is little anyone can say to ease the continuous, crashing waterfall of pain. You may experience strong physical pain, struggling to complete even the most basic tasks of daily living.

“ I just wanted to curl up and die.”

Feelings of shock, disbelief, and a sense of numbness or unreality, too, are completely normal immediate reactions. They may serve to cushion the impact of the loss until you are more able to face the devastating reality of your child's death. This numbness often begins to wear off after six to eight weeks when you may experience your grief more intensely. This sometimes coincides with the time when visits/calls from family and friends slow down too.

“ I felt so alone and immobilised, watching everyone else getting on with their lives.”

After the death of your baby/child, it is not unusual to feel isolated and lonely. Telling others of your child's death can be extremely difficult and may cause much distress. Going shopping, meeting neighbours in the street and taking other children to school can all seem overwhelming.

There may be times when you withdraw into yourself and lose interest in everything around you. It may take weeks and often months before you feel able to return to daily activities.

“ I totally broke down. I isolated myself from my family and had no energy for anyone - only enough for survival.”

Below are some normal and common responses experienced in the first weeks and months following the death of a child:

- A feeling of shock or **numbness** is a very usual response to a sudden loss. This is often what gets people through the first few months. It is the way your body protects you from the full force of the tragic reality.
- **“If only”** - This continuous inner dialogue is an understandable way of wanting to go back in time and try and change things so that your child does not die. Feelings of resentment and anger can be overpowering. The implicit belief that bad things should not happen to good people is seriously challenged.

“*If we are really good people and we give our whole heart to the bloody community and to everyone, our friends and family, there is the fact that we just don't deserve it. And it's so annoying. I know so many people ... actually I shouldn't say it...well, you feel like saying that person deserves it, not me. They're the assholes, not me.*”

- It is not unusual to get **‘flashbacks’**, especially of the moment that your baby/ child died. These strong mental images are a reaction to trauma and may appear ‘out of the blue’. They may cause tension, anxiety, guilt, bad dreams, and the feeling that you are losing your mind. These should soften and reduce in frequency over time.

“*I always have flashbacks since then, from the moment the doctor told me that X's heart stopped, and my wife started to cry. God, this is the worst feeling I ever had, and it is still going on. Crying might help a little bit.*”

You may experience panic attacks and feel out of control. Letting the feelings run through you, taking slow, deep breaths and consciously relaxing your tense muscles will help the feelings of panic disappear. You may like to join a yoga class or use a relaxation tape to help you go through relaxation exercises.



- Feeling **irritable** with little things others consider important - your world has been turned upside down, yet others continue as if nothing has happened. It is perfectly normal to be offended or perhaps feel anger at the unfairness of it all!

“ I was inwardly screaming about how incredibly unfair life can be! I find it hard when you read about the kids who have had these horrible things done to them by their parents, or that they just don't care, and you do care absolutely. It's a very hard point.”

- It can be **hard to make decisions** on practical matters – most grieving parents experience great pain and distress deciding what to do with their child's belongings. Some people feel frozen in time when their child dies; others seem to throw themselves into action. For many parents, it seems to be perfectly fine to leave things just as they were the day their child died, yet for others, the belongings are too sad a reminder of their loss. In most cases it is best not to make any big decisions about belongings for a while, as you can change your mind about how different things affect you. It can take some time before you will be able to think rationally and constructively.

Holding onto any experiences, memories, or mementoes you have of your child can be affirming and restorative in the future.

“ We have a back cupboard and you can open up the cupboard with all her play things there. Bethany's room would still be as it was, had we not moved house.”

“ Sometimes I can be with Sian's things without crying and sometimes I can't. Her school bag is still in the laundry, where it was every night after school and her room is the same. I have bought things to put into her room since she died, and people give us things for Sian's room. I can't ever imagine, unless I suppose if we ever had another baby, that we would pack it up. It gives me peace that her room will be her room and Dane, her little brother, can go in there at any time and play with her things, just like they used to when she was alive.”

You might find a time comes when holding on to your child's possessions no longer feels right or circumstances may arise that break the connection.

“ The back room has the double wardrobe and it's full, just full of her things. I had to go and look for something and it was the first time that I opened the wardrobe and saw her special boxes and I was a mess. Charlotte was helping me and goes 'Mummy, these are all cupcakes'. Everything was cupcakes, a cupcake clock, a cupcake hook thing. I wish I could actually enjoy those things but they all smell awful now. They don't smell like her at all, they smell like storage. It sucks! I didn't expect it to be there still but I couldn't believe how different it smelt.”

“ Every Friday night, I would light candles around the house and in front of her photo. Her brothers were at the age that when they saw a lit candle, they would blow it out. That was okay. I couldn't get cross with them.”

- **Feeling disconnected** with the world – After a sudden and unexpected death of a child, it is common for bereaved parents to feel isolated and alone and unable to really identify with the rest of the world. You can find yourself becoming forgetful, impatient and unable to concentrate. You might experience anxiety, guilt, despair and overwhelming confusion and life suddenly seems to be “out of control”. Physical reactions such as changes in appetite, sleeping difficulties, fatigue and a general feeling of being unwell can also be experienced. These are all part of grief and are common responses to loss.
- Dealing with the **reactions of others** – There may be people who are too uncomfortable or too overwhelmed to visit, call or send a note at the time of your tragedy. Later they may feel too embarrassed to cross paths with you. Others may minimise or misunderstand your grief. Many people do not understand the power, depth, intensity or duration of parental grief, especially after the death of a child.



“ Sadly there have been some friends who have found our journey too confronting or difficult and we haven’t seen or heard from them since Iris’s funeral, and perhaps we’ll never see them again.”

The fact is that most people in our society have not had open discussions about life and death issues nor do they seem to know how to talk to others after a death. Many parents feel they have reluctantly become the ‘expert’ and so you may find yourself needing to take the initiative in talking about your child so others will know that it is okay.

Family and friends are often deeply distressed when someone close to them has a child die. They may feel incredibly helpless and powerless and wonder what they can possibly do to make the family ‘feel better’. Sometimes they add to your sadness through insensitive remarks.

“ Sometimes, well-meaning friends have said things like: ‘She’s in a better place now’. Comments like this have upset and angered us, since the very best place for her would be with us.”

Writing a letter to let family and friends know how to support you can be easier than telling them face to face. Here is a poem that you might like to show someone you know:

*PLEASE, don’t ask me if I am over it yet.
I’ll never be over it.
PLEASE, don’t tell me “He/She is in a better place.”
He/she isn’t here with me.
PLEASE, don’t say “At least he isn’t suffering.”
I haven’t come to terms with why he/she had to suffer at all.
PLEASE, don’t tell me you know how I feel.
Unless you have lost a child.
PLEASE, don’t ask me if I feel better.
Bereavement isn’t a condition that clears up.
PLEASE, don’t tell me “At least you had him for so many years.”*

What year would you choose your child to die?

PLEASE, don't tell me "God never gives us more than we can bear."

PLEASE, just say you are sorry.

PLEASE, just say you remember my child, if you do.

PLEASE, just let me talk about my child.

PLEASE, mention my child's name.

PLEASE, just let me cry."

At the same time, the support of family and friends can be invaluable to bereaved parents. In fact, it can greatly affect how a family will 'get through' the months ahead.

“ Good friends have been able to hear our distress and we have weathered the storm of well-intentioned, but poorly thought out comments.”

“ Watching my parents has also been harrowing. Iris was their first and only grand-daughter and they were totally smitten with her. Not only have they experienced their own extreme grief over losing Iris, but they have also agonised over seeing Rob and I so broken. Through all of this they have helped us with amazing emotional and practical support.”

You might find it helpful to pass on a copy of the Red Nose Grief and Loss booklets “To Family and Friends: you can make a difference” and “Grandparent to Grandparent”.



A guide for family and friends

Death is a difficult subject and sometimes it is hard to know what to say or do to someone whose child has died. But don't let your own sense of helplessness keep you away. Silence and distance can be hurtful, not only to the parents, but also to you and your relationship with them.

As you cared about your friend or family member before the death of their child, show them, in some way, that you still do. Your understanding and support will make a difference.

What you can do:

Be there. Come to the house or call to say: "I care and I want to help."

Listen! Even when talking about the baby or young child or circumstances of death make you uncomfortable. This is not about your comfort.

Remember that it is usually the simple things that mean so much.

Freely recall the baby or young child by his/her name. This is an important way of acknowledging the child's existence and importance.

If you have organisational skills, take the initiative and be an organiser. Put together a list of friends and relatives willing to bring meals to the bereaved family for several weeks after the death. Be available to run errands, clean the house and even feed or walk the dog.

Consider both the practical and emotional needs of any siblings. How long has it been since Jack ate anything? Does Amy need someone to cuddle? Organise 'play dates' with your own children.

If you would like to give the bereaved parents a gift, consider a locket for the child's picture, a special box in which to keep mementos of

their child, picture frames (especially for siblings) or framed poetry, or a vase for flowers.

Consider how long you think it would take to “get over” the death and then forget it! In fact, there is no time limit. Grieving is tough work that takes much longer than most people expect. Most parents say it takes two to three years to feel ‘half normal’ again and, even then, there is the strong need to remember and maintain the strong bond with their child forever.

Remember important days such as birthdays and the anniversary of the death. A call, a visit or a card can mean a great deal to grieving parents who are wondering if anyone else remembers.

Do feel free to say any of these things:

- I’m sorry
- I can’t begin to imagine your pain
- I feel so sad that you have to go through this
- This must be extremely difficult for you
- I want to do whatever I can to help you. What can I do?
- Talk for as long as you want. I have plenty of time to listen

Red Nose Grief and Loss booklet **“To Family and Friends: you can make a difference”** is very informative.



You and your partner

As individuals, you may find that your thoughts and reactions during bereavement are often different from those of your partner. It can be hard to maintain effective communication in your relationship while you are experiencing such intense feelings of grief and sadness. This is particularly so when one of you seem to be “getting on with life” and the other is continuing to be overwhelmed by the grief. It can seem that one has forgotten and doesn’t care about the loss, or that the other is not coping.

“G returned to work. He was resilient. After I while I saw him as not grieving as I didn’t understand that he was grieving differently. I thought he lacked compassion and didn’t love our son. How could he keep going? How could he function and ignore ‘the elephant in the room?’”

Everyone grieves differently, even couples who have known each other for years. For some couples, the death of a child brings with it an increased intimacy, as you cling to each other for survival. For others, this can be a period of instability and distress in your relationship, with needs being mismatched.

“After Jessie died we went into survival mode in our relationship. My husband became very needy, but I had nothing to give. The more needy he became the more I moved away... I needed space, but he wanted to be loved more.”

“At first we were in sync, close together. He was so supportive of what I needed to do...ten months after the death P received a promotion and said it was the first ‘alright’ day since Samuel died, but I had had a particularly bad day that day. He resented me because I could not be happy for him. I needed him to be miserable like me.”

Virtually all couples find that they grieve differently. What is important is to learn to respect each other's different ways and timetables of grieving, and to allow each other space and time to grieve in the way he or she needs.

“ I needed to talk to people other than my partner and hear about their experiences. Normalising my experiences was important to me. He didn't have the same need.”

“ We still share the grief one hundred per cent, but we are a hundred miles apart in how we see things.”

Having sex may bring back memories and renewed grief. It is quite common for one or both bereaved parents to feel guilty about feeling any pleasure, or to think that they are somehow letting their baby down by starting to have sex again.

“ I felt that having sex would be like a step towards forgetting our son – that we would be moving on and trying to replace him – even though we weren't trying for a baby.”

But feeling pleasure doesn't mean you have forgotten about your child or that you no longer care about him or her. Try to remember that it is perfectly alright to enjoy sex and other things in life even when you are grieving.

When you do have sex, one or both of you may find that it releases strong feelings you had not expected. This is quite common and nothing to worry about. If it happens, try holding each other until the feeling subsides.

“ When we did eventually have sex it was so emotional. Overwhelming even. It continued to be very emotional for a number of weeks.”

Talking openly and honestly about your own feelings with your partner and listening to each other's needs and expectations can be helpful. Just as sadness does not mean you are 'not coping', 'getting on with life' does not mean that a person does not care. You may just be experiencing grief differently. Your partner cannot be expected to meet all of your needs and it may be helpful to have others to talk to.



“ Leanne expresses her grief more openly than me. She does more self-help stuff too. I am not your typical male however. It wouldn't have been right for me to shut up and get on with it. I would have ended up in the 'funny farm' otherwise.”

“ It has been heart-wrenching to observe the pain and suffering endured by my darling Rob. Sometimes I have nothing left to offer him by way of comfort and I have to let others support him or just watch as he struggles on by himself. Mostly, though, we have been able to cling to each other and ride the waves of grief together.”

If you do not have a partner, it can be harder to have your emotional and physical needs met. It is important to have someone with whom you can share your thoughts and feelings at this time. Reaching out to family members, or just taking the time to see friends, can often be surprisingly helpful.

We recommend you look at the Red Nose Grief and Loss booklet: **“When Relationships Hurt, Too - the impact of grief on parents' relationships after the sudden death of their child.**

What a professional can offer

No one can 'solve' the problems of a person impacted by the sudden and unexpected death of a young child - indeed how could anyone ever 'solve' or 'fix' this problem?

A bereavement counsellor can, however, assist with the grieving process by acknowledging and normalising feelings and experiences, providing accurate information, identifying resources and suggesting options that you can pursue in your own time. Most importantly, such a relationship can provide constant support and validation of the small but terribly difficult steps that must be taken in order to feel re-empowered as individuals, parents and family members.

“It wasn't until about a year after Madeleine's death that I felt like I was ready to start talking about the experiences I'd had. Once I started seeing a counsellor one-on-one, I started to get a better idea of what I was going through and Jeanette started seeing the same counsellor. It allowed us to gain insight into how each other was grieving. We were better able to understand the things that got us down and those that stopped us functioning. We were able to discuss ways of supporting one another and of avoiding shutting down. It was a challenging time, but one of tremendous growth in our relationship.”

“There is a limit on how much you can do to help yourself. Get professional help even if you don't think you need it.”



Support groups

Many parents feel better just knowing that others feel, or have felt, the same way. So this may be the time to connect with a trained volunteer or become involved with a parent support group.

Support groups at Red Nose Grief and Loss, for example, are co-facilitated by a counsellor and a trained Parent Supporter and provide an opportunity to talk, be understood, to share and to help normalise feelings and experiences.

“ It helps to meet others in support groups and see how they are coping. This helped us and gave us hope, especially hearing from parent supporters. They showed us how you can heal and that you can go on to have other children.”

“ Accept that men are more likely to grieve privately and talk only with their partners and more women prefer group support.”

Red Nose Grief and Loss provides bereavement counsellors, volunteer support from trained bereaved parents, support groups, creative arts sessions, a personal enrichment program (PEP) and remembrance activities.

If you would like to talk to a counselor contact **Red Nose Grief and Loss** on 1300 308 307.



The creative arts – one way of expressing grief

Support that is offered to bereaved parents often relies on talking as a way of expressing grief. Yet there are some human experiences that are so complex and so intensely emotional that words alone cannot do them justice. For many people, the death of a child is one of those experiences. Sometimes it is too hard to find the right words to adequately express grief, and other forms of expression seem to better tap into our deepest thoughts and feelings.

The following pictures illustrate the powerful emotions that can be evoked through the creative process. The mother, responsible for the art works, was one of many bereaved parents who participated in a series of Creative Arts groups that were held at the Victorian Red Nose Grief and Loss office.

“When I reflect on the process and look at the piece of work that I and others have created, it helps me find peace with my thoughts.”

“These classes are a time to be myself, away from the usual routine, and to reflect on my feelings and express myself without judgment. You don't need to be creative – it's about choosing materials and using them in any way to express your emotions, in the past, present or future.”

R's daughter, Iris, died suddenly and unexpectedly when she was 3 years old. The following pieces of art were created by R. during the Art sessions, reflecting very powerfully her journey of grief.



“ This was the first piece I made at the first art group I attended. It was only a few months after Iris’ death and I was feeling completely chaotic, which is what I see when I look at this picture.”



“ This was this the first piece I made at the second art group. I was feeling so, so sad and just wanted to put my tears down on paper. There was something very soothing about drawing all of those tears, and I left the group feeling ‘lighter’; unburdened, at least for a little while.”



“ I painted this piece at the end of the first art group, which was also the end of the year. The invitation was to make something which represented how we felt about the new year. The image I had in my mind as I made this was of being in the jungle, thick with vines that I have to some how find my way through.”



“ I really enjoyed making this bird from a pine cone, tissue paper and a sardine tin. I thought of my own 'little bird' Iris, as I made it and it allowed me to tenderly connect with her again.”



“ This piece was such a relief to make. It represents an image I have had in my mind from the first days after Iris died. I imagined my heart had been ripped from my chest and that I could only hold it together temporarily with string, rubber bands and paper clips. In the weeks after Iris died, if I was away from home for too long, I could physically feel my 'scar' opening up and I knew I had to get home. It really helped to see this feeling, which I had imagined/felt for so many months”



I am an inspiration

“ I am an inspiration...

The fact that I got up out of bed makes me an inspiration.

That somewhere along the line I chose to live.

That I could swallow food again and even taste it.

That I no longer feel guilty about laughing.

That I walked out my front door the first time.

That I showed my face in the community, and even spoke to some people.

That I can still allow myself to cry ... and laugh ... and remember... and mention my child's name.

That I am a pioneer in how to 'handle' grief ... I allow others to do the same.

That I can look at my other children and really love them.

That I can let them out the front door and they are not wrapped in cotton wool from head to toe.

That I can allow them to spend time away from me.

That I can still feel.

That I can take my partner's hand and choose to keep going.

That I can let my partner take my hand to keep me going.

That trivial things no longer matter but I can still listen to my friends "go on".

That I can still make love to my partner.

That I can still have another child and love them with my heart and soul.

That I can look at another person who has lost a child and "just know".

That I can still smell a rose.

That simple moments are the most important things in my life.

That I want to help people.

That I'm allowing myself to discover me.

That I can really live.

I am an inspiration"

Mel Ryan (mother of Danielle - four and a half)

Surviving special days

It is common for things or events to trigger painful memories. Anniversaries, birthdays, family celebrations, a photo, a song, a baby or child of the same age are some of them. It is important to know that these are normal reactions and that other grieving parents share this sensitivity.

“ Four weeks later it was her third birthday. This day loomed on the horizon with equal, but opposite, intensity as the day of the birthday party we had been planning just a few weeks earlier did. We decided to complete the chook house and fill it with four Faverolle hens as a gift to her. I also cut up her dresses and sewed them into prayer flags which are now threaded through the gum trees around the chook house. We had birthday cake, cards and tears.”

“ Fortunately, birthdays, anniversaries and other holidays do get easier with time.”

Grieving parents have explained that the anticipation of pain on a holiday or special day is often worse than it actually turns out to be. Be warned, however, that many also report that they ‘crashed’ the day after. Not realising how much they had psyched themselves up, and in some cases forced themselves to participate in things they really didn’t want to be part of, they temporarily reverted back to the confusion and depression of those first few months after the death. With time, this pain in most cases will lessen.

“ I have learned, with time, to find peace and comfort in celebrating the memory of our daughter. On her birthday I prepare myself for a long ride filled with a lot of happy and sad tears...because now the joy of having had her is greater than the sadness of losing her.”



The following is what helped one mother to grieve and to commemorate her son, who died from Sudden Infant Death Syndrome.

“ I kept a diary, though after one and a half years I didn't write as much.”

“ Since Easter came right after his death, I went to his grave site with a toy.”

“ On Mother's Day, I bought a locket to put one of his pictures in. Now I don't leave home without it!”

“ I had two pairs of his shoes bronzed: his first, and the pair we bought just two weeks before he passed away.”

“ I went through his baby book and I framed a few of my favourite pictures.”

“ At Christmas it was very hard for me because he was with us the Christmas before. I took one of the pictures of him with all of his toys and placed it inside one of the Red Nose Grief and Loss Christmas cards and mailed them to family and friends.”

“ On his birthday I bought a card and put it in his baby book. I plan to do this every year. I went to his grave and placed a toy there. I also bought cupcakes and a gift for one of his day-care playmates. I burned a red candle in his memory all day.”

“ I find it very important to keep talking about my son to people and to make them realise how important it is for them to talk about him to me. It's all part of the healing process.”

“ I keep a picture of him on my desk at work, which sparks conversation about SIDS and creates more awareness.”

“ I have been very involved in SIDS-related activities. This helps me to feel a sense of belonging. My attitude is that I should do as much as I can for Red Nose Grief and Loss because that's the only thing I can still do for him.”

Kids grieve too

Children are always affected by a death in the family. However, because they cannot understand or talk about death in the same way as an adult, they will sometimes appear to deny it or seem unconcerned. They might misbehave, have nightmares, and revert to bedwetting or other habits which they have previously outgrown. They may become 'clingy', withdrawn or even laugh without cause.

The youngest ones cannot tell of their fears and find explanations hard to understand. But whatever their age, it is important they be told the truth as simply as possible. Straightforward and truthful explanations are best such as "Our baby died from something called S.I.D.S. We do not know what causes it but it will not happen to you or to Mummy or Daddy".

“ Just being honest with the kids mattered, involving them, without being too pushy.”

“ Charlotte (aged 5) asked questions like 'Is Bethany coming back?' 'No. She's dead. She is never coming back.' That's my way. Someone of a more religious faith might not put it that way. I am a pretty straight down the line bloke who doesn't bullshit that much. I found honesty to be the best way. That was the same actually in hospital. I don't have a religious bone in my body but the chaplain lady, she came around and said 'Do you mind if I offer a prayer for Bethany?' as simple as that. But then I said to her 'Who am I to say that Bethany would not have been religious, she may have been, or she may have been a complete atheist, whatever. And it is not my right to tell her to be religious or not. She can be anything she wants so offer her a prayer and if that's taken up somewhere else, so be it.' It's not my decision. She could have been whatever she wanted to be.”

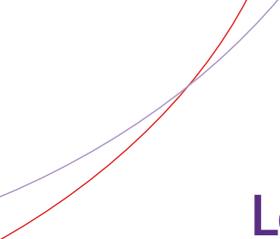


Children need constant reassurance of their parents' love and affection. However this can be extremely difficult for parents, especially in the days immediately following the death. Some parents may have difficulty providing such reassurance while their own grief is so acute. Other family members can be asked to fill in here.

Children also need reassurance that neither they nor anyone else was responsible for the death and they will not die in the same way. Later, as children grow and their understanding develops, they will have further questions and may want to talk about why their sibling died.

All children benefit from being allowed to express their feelings. Older children may need encouragement to discuss their worries openly. School age children can benefit from being asked how they would like their school friends to be told. For example, children may want to tell their friends themselves, or they may prefer a teacher to do this for them. This allows them to be part of the decision making.

We recommend the Red Nose Grief and Loss booklet **“What About the Other Kids?”**



Looking after yourself

- Remember to look after yourself, emotionally and physically. Eat well. Physical activities can energise you, nurture your spirit and provide a focus outside your grief. Try meditation, yoga, massage, long walks and bike rides especially in natural and beautiful environments.
- Find people with whom you feel safe who will just listen and be with you without judging.
- Cultivate activities which help maintain your connection with your child in whatever way is most meaningful to you and your family, and which honour his or her life.
- Accept that you will have flashbacks and that grief will well up periodically. Coming to terms with the death could take many years, possibly the rest of your life.
- Try not to make hasty decisions about relationships or anything else.
- Remember to seek support when you feel you are struggling, whether it is through counselling, support groups, on-line chat rooms or forums. Speak with other bereaved people, especially those you feel safe with and who will just listen and be with you. This can help to normalise your own experience and provide you with new strategies.



Looking to the future

When reflecting on parental grief, we know that the bond you formed with your child extends beyond death. Surviving will be a constant struggle, trying to adapt to a new reality that is forced upon you and, at the same time, trying to make your child who died a part of your lives forever.

“ Be patient! Grief is a long and painful process, perhaps endless, but the way you deal with it and the way it affects your life and relationships, changes with time.”

“ You will be able to be social again, feel joy again. Give yourself time. It could take years or months, it is hard to know, but accept that you will laugh and find meaning in life once more.”

“ I don't believe that time heals, but with the passage of time, we have found ways to adjust to our new reality. I'll never, ever forget my daughter. Her memory is part of me.”

“ We have understood the preciousness of life, of any relationship. This puts everything else into perspective. Other things which used to be important are now not.”

Probably the most important step for parents in their grief journey is to allow themselves to heal. Healing does not mean forgetting. Parents need to be good to themselves, absolve themselves from guilt and not be afraid to let grief loosen its grip when the time comes.

“ We are different parents now, more relaxed and calmer and don't stress over such minor issues such as a messy room or a spilled drink.”

“ It seems like I am growing and learning a lot, and I guess I am. Certainly we have been given much by friends and strangers. I would give it all back and un-learn the lessons in a second to have Iris back again”

Parental grief is a grief which is accommodated, not ended; lived with rather than gotten over. It is clear that, in some form, grief is always carried. However, this does not mean that parents do not function or create fulfilling lives for themselves.

“ We have come through one of the biggest tests of any relationship. We have survived the most treacherous terrain and it was damned hard. It has brought us closer together.”

“ After a year I began to put makeup on and do my hair, which was so unusual, he thought I was having an affair.”

For many parents, learning to be more forgiving of themselves and others, being less controlling, valuing their other children more, becoming less materialistic and more spiritual, this has all helped the recovery process and led them to strengthening their relationships. Determined to focus on their strengths, not on what they have lost, some parents commit to living a life their child would have been proud of and, in the process, become stronger and closer as a family.

“ Keep on living – until you feel alive once more”



Questions about another baby

It is very common to raise the issue of having another baby immediately. Some parents feel that it is the best thing for them to do whilst others feel that they can't face the prospect. It can be a difficult decision to make because, while there is often a longing to fill the emptiness and loneliness, there can be anxiety and panic that the same tragedy will happen again.

In making the decision, you need to be aware:

- That there is better than 99% chance that another baby will not die from SIDS/SUDC (Sudden Infant Death Syndrome/Sudden Unexpected Death in Childhood)
- No baby can replace another. Each child is an individual with his or her own personality and characteristics.
- If the next baby is born close to the next anniversary of the baby's death or birthday, conflicting emotions such as celebrations and sorrow can be confusing and difficult.

“ We decided to wait six months before trying again. I thought it would give us more time to heal and make it less likely that our next baby would be born on or around the anniversary.”

The decision as to whether, or when, to have another baby should be made when you feel ready. This may be immediately or it may be later.

“ Although we could never replace Samuel, we had never wanted Hannah to be an only child so felt we had to get pregnant very quickly. There was little intimacy, however, as sex was for the sole purpose of having another child. It was simply a means to an end.”

“ Another baby does help with the healing and growing as a person.”

“ If it was for me, I wouldn't have tried for another baby. Also, I had to accept that medical advice can only help so far, that there was always the chance of it happening again.”

We recommend the Red Nose Grief and Loss booklet **“Another Baby? The Decision is Yours”**.



Individual reflections

Rachel's daughter Iris died just before her 3rd birthday, on July 25, 2007.

“*Losing Iris has challenged everything I thought I knew about myself and my beliefs about the world. I thought that ‘these sorts of things’ happened to ‘other’ people and maybe I naively thought that trying to live consciously, gently and with heart somehow protected me from such extreme tragedy. Of course, I have done a lot of reflecting, questioning, ruminating over the past five months. I have spoken to many good people about death and Iris’s death in particular. There is no answer to the question of how she died; and, there is no satisfactory answer to the question of why she died. The only answer that speaks in any meaningful way to these questions is that ‘death is just part of life.’ This, I think, is the most frightening, and yet liberating, truth I am learning to embrace.*

I had an epiphany of sorts a few weeks ago as I walked, tears streaming down my face, along the riverbank with Hugo in the pram and two dogs by my side. I was ruminating on the hundreds of times I had done the same walk with Iris, pointing out birds, koalas and funny looking dogs, or explaining to her about shadows, or the wind, or clouds. Then I remembered Hugo and how he needed just the same from me. That moment started me thinking about love and about how it is truly an act of love to continue on living and living well after one has lost love in such a sudden and tragic way. Until that point, I had been rendered quite powerless in the face of death and the looming path of grief that lies ahead for me. However, I have started to feel occasional moments of peace since embracing this idea.

The following Michael Leunig poem speaks well of such things:

*“There are only two feelings. Love and fear.
There are only two languages. Love and fear.
There are only two activities. Love and fear.
There are only two motives, two procedures,
two frameworks, two results. Love and fear.
Love and fear.”*

Living in love, not fear, means embracing the deep grief I feel and understanding it as a continuation of the deep love I shared with Iris. Living in love means keeping my heart open to Hugo, Rob and my step-daughter, Eliza, and not pushing them away or smothering them, out of fear of losing them.”

Brenda's grandson Riley died at 20 months in 2009

“ On 27th July 2009 our world came crashing down when we lost our gorgeous grandson, Riley Robert. Our entire world changed that very day and I don't think we as grandparents will ever get over it.

Our grief was so real and so raw and, to add to that, we had to watch our beautiful son and his lovely wife lose their only child of 20 months for no reason. For them to continue on with life by living in the same house, which was their family home, is beyond my comprehension. Somehow we all kept breathing and attempted to comfort each other, particularly Riley's Mummy and Daddy.

Friends and extended family tried hard to comfort us but, on my part, I preferred my husband to take their phone calls because few of them knew how difficult it was for me to actually speak and neither, for that matter, did they know what to say or how to communicate with us in our grief.



A very close friend of mine used to say that she just wanted to hear my voice. I thought that was a particularly odd thing to say to me over the telephone ... my voice never changed - what was she thinking? Anything that was said to me was taken personally by me and I seemed to change from the very considerate person I was into a very intolerant one. I couldn't put my finger on why I was changing so much and so quickly. All I knew and felt was that my heart was broken. How many of us do actually suffer from a broken heart? We think we do... like when our pet dies, when our first love is finished or even when our elderly parents pass away, but that is nothing to what a grandparent feels when their grandchild passes away.

I want to stress to people on the outside that they cannot make things better for us...we have to travel at our own time and we just have to set our own pace. Nothing in my life seemed to matter one bit other than the gigantic loss of beautiful Riley. 'Why had God chosen to take him' was my most common sentence used over and over in my head.

This week we celebrated what should have been Riley's sixth birthday. Oh, if only he was with us all to hug and kiss him and to blow out his candles. To say that we still miss him is an understatement. We try to imagine how he would look now, but our feelings hit a brick wall. All I imagine is his mass of beautiful curls and, oh, how I ache to touch him.

I just want to conclude by saying life does go on and we still keep breathing. Our lives will never be the same, but we have to thank God for the other blessings we do have."

The friend of a bereaved mum pays tribute to Jude who died at 5 years of age from an undetected heart defect in 2011.

“ Jude was the kind of child who took your breath away. When he died, two days before Christmas 2011, it was sudden, unexpected and incomprehensible. This cheeky, knock-about

five-year-old, whom we all thought was indestructible, was my oldest friend Fiona's boy. His death, from an undetected heart defect, left a hole so enormous I couldn't believe it wasn't leading the 6 o'clock news.

I had no idea about how to talk to the bereaved. Until then, I'd mostly avoided those who'd lost loved ones. I didn't know what to say, so I said nothing. In a culture that's distinctly uncomfortable with pain, this is a safe position for many people. We don't like to look that kind of loss in the eye for fear it might swallow us.

For Fiona, one of the hardest things in the aftermath of Jude's death was feeling as if he was being erased. Some people would say anything to avoid talking about him, terrified it would trigger more hurt. It had the opposite effect.

She told me: I'm not over the death of my baby boy and I never will be, so the mention of his name doesn't remind me that he died; it lets me know that people remember that he lived. Nearly two years on and her sense of loss remains ever present. By any measure, she will always be grieving. But she is not ill. She has simply found a way to accommodate her pain.

In December, as she prepared for the first anniversary of Jude's death and another Christmas without him, she swapped the traditional advent calendar for a journal that marked one thing each day that she was grateful for. I was, and still am, in awe of her resilience and capacity for love.

How, I wondered, does she do it? Her explanation simultaneously reassured and devastated me: 'I need people not to misunderstand my sense of being okay. They shouldn't decide that I've moved on, accepted my loss or, God forbid, replaced my precious son. Instead people should know that it's possible to choose to be okay whilst at the same time living with a broken heart.'



I can never replace what Fiona has lost, but I can promise her I will never say, 'enough now.' I will never tire of hearing her talk about Jude, and I will continue to remember her crazy-beautiful boy and say his name out loud for as long as I have breath in my body." (Published in the Sydney Morning Herald 16/10/13)

Leesa's daughter Memphis died suddenly and unexpectedly at 15 months.

“ Thank you for letting me talk about my experience. I hope that what I write will help another parent to deal with the loss of a young child. When speaking with the coroner they may refer to your child as a case number and not as a person; I found that, by referring to Memphis as her mother and saying her name when they referred to her as a number, by the end of the call they were saying her name and not her case number.

Memphis passed away at home, so when the paramedics and the police arrived I was taken away from her for questioning. This was so intrusive and the feeling was horrible. I was made to feel like it was my fault; I know they were just doing their job but they should have approached it in a better way. We then had to go to the hospital with Memphis and were made to walk through the emergency department with Memphis wrapped up in her blanket. They took us to a room where we placed her in a cot. We then had the social workers and doctors coming in and out of the room asking questions when all her dad and I wanted was to just hold her. The police arrived again for more questioning.

Leaving Memphis in the hospital was the hardest thing I'd ever had to do as leaving meant she wasn't ever going to be coming home with me again.

When the coroner contacted me to say that they had done the autopsy and Memphis's body was ready to be released, I hadn't even made funeral plans for her. The coroner made me feel at ease by telling me that Memphis was safe there with them until I was ready to make the funeral arrangements.

When planning her funeral we had a lot of help. We wanted the funeral to be bright and colourful just like our baby was. We made everyone wear a bright piece of clothing and, rather than having flowers, we asked people to make a donation to Red Nose Grief and Loss and Kids on Memphis' behalf. I asked the funeral director if I could dress Memphis for the funeral as I needed to hold her and dress her one last time. It was very hard to do, as she wasn't the same, but she still looked like my 'lil ladybug'. We didn't have a viewing for family or friends, as we wanted everyone to remember the beautiful cheeky little monkey she was, always with a smile on her face and her thumb in her mouth.

Grief is such a journey - I have good days and then I have extremely low days, always up and down with emotion. Some wonder how I can go on and how I can be so strong, but strength has nothing to with it. I know my baby is up there looking down upon me and she wouldn't want me to be sad. She would want me to talk about her and remember all the amazing things she did. Everyone's journey is different and there is no right or wrong way to grieve. What helps me is talking about her everyday and making sure that her memory is always kept alive.

I was in a new relationship when Memphis passed away and it has been hard on both of us. Steve has such a huge heart and is an amazing person to stick by me and to keep me motivated when all I want to do is fall in a heap. Talking to him about Memphis and how I'm feeling helps, although I don't like to cry



in front of him as I know it upsets him to see me sad.

Communication is the key to getting through this as a couple; some days you may not feel like talking, but other days all you want to do is talk.

DON'T ever be afraid to talk about your child, if someone doesn't like it then they can walk away. DON'T ever be made to feel like you can't mention your child's name because they will always be a part of you. NEVER blame yourself for what has happened; it wasn't your fault.

It's coming up to Memphis' first year anniversary and her dad and I have decided that we will release balloons for her and write messages on them for her.

The firsts are so hard as it still doesn't feel real. Take each day as it comes and don't push yourself to do anything. I find that, with the anger part of grief, using a punching bag helps, as it releases the built up tension inside. So much more that I want to say, but for now this will do."

Pete and Georgie's son, Sam, died on the 22nd June 2012 at 21 months

“ On the night of June 22nd 2012, I went to check on Sam before I went to bed as I always did. I was surprised to see him on his tummy in his cot as he had always slept on his back. When I tried to roll him over I knew straight away that he wasn't OK. He let out a big gasp of air and didn't wake. After turning on the light and seeing his colour it was obvious that he was gone. I had never seen a dead person before but I knew this must be it. He was blue and not waking. I would have normally got my husband for anything medical with Sam, as he is an Ambulance Paramedic, but he was working that night. I called 000 and went through the typical questions, all the

while thinking that my husband would most likely be the local ambulance called to this job. I was instructed through the CPR steps and carried them out with difficulty until help arrived. For a short time I thought Sam might be coming back as his typical colour was returning, but, in hindsight, I think it must have been because he was on his back now during the CPR.

There were multiple ambulance crews that arrived on that night. It seemed there were strangers everywhere. After it was confirmed that Sam had died, we were given some time with him in his room before being told we would have to take him to the hospital. I knew this meant that I would have to leave him there, which I couldn't imagine doing. I thought 'just go along with it for now and deal with that when you get there ... throw a tantrum, cry uncontrollably or whatever it takes'.

We dressed Sam before going to the hospital because his pyjamas had been cut off by the paramedics. His body was starting to get cold and I can remember just wanting to dress him in more and more clothes to stop it happening.

There was some questioning at the hospital and I remember the Police requesting to see his body. They apologised for having to do so and told us it was part of the protocol. Pete undressed him and it was horrible to see his body starting to change already. I was shocked that my connection with his body was deteriorating as it changed so quickly. I felt betrayed and angry that he was leaving us. I felt mixed with confusion, shock, fear and the big WHY, that we will never really know the answer to.

The Police interview began when we returned home from the hospital. I was grateful that we didn't have to go through that whilst still having our last moments with Sam at home. The Police were apologetic and respectful despite having to ask the confronting questions. The photographing of his room was



something I will never forget. Despite having no doubts about the safety of his cot or sleeping environment, the interview and photographing seemed like something straight from a crime show on TV. As I was home alone with him I couldn't help but feel responsible. Toddlers aren't supposed to just die in their sleep. I knew about SIDS and had always followed the safe sleeping advice but thought that the risk of this was for newborns, not a boy approaching two years old.

The planning for Sam's funeral was strange to say the least. We took it in 'baby steps' I suppose, and tackled each decision one at a time. We were stuck on the choice to bury or cremate. Pete wanted a cremation and I hated the thought of either. I remember my sister saying how she can understand my indecision. "They both suck! If only there was an option C, we would take that but, really, all we have to choose from is bury or cremate".

We had the celebrant, who married us five years earlier, conduct Sam's funeral. She did an incredible job and I will always be grateful that she could do this for us. We lit a candle for Sam at his funeral and decided that this would be something that we would have in our home and light at all the special occasions down the track to signify him being with us always. We got a hurricane glass vase to display the big candle in and surrounded the base inside with some sand from his sandpit. I love that we have this now forever and it always warms my heart to have it lit at home.

I knew there would be a great number of people there and felt desperate to collect any memories these people had of our boy. The celebrant asked everyone to write a memory they had of Sam on little cards that were handed around and leave them in his little backpack for us to keep. Knowing there would be no new memories of him, these are always something I'll treasure.

If I could add to this now I would have requested our friends and family to send us any photos or videos they have with Sam.

A few people had sent a photo after a year or so, which made me feel so cheated that I hadn't had it to cherish before then. Someone said they didn't think I'd want their photos as it would upset me. Clearly this was an assumption, like many others for grieving families, that are so hurtful.

Surely there is no greater loss than losing your child. For me it felt like a double hit. I lost my boy and lost my role as a mother - no one to look after and care for, except each other. We were left with a quiet and empty home that was so lonely. There was much encouragement for us to go away and have a break together, which was all from well meaning family that cared for us. I didn't want to go anywhere. Despite our quiet home being an obvious reminder of our loss, it was also the place that we had the strongest connection with our boy and all the memories that came with it.

The process with the Coroner's investigation was lengthy and frustrating. Neither of us were expecting answers, although hopeful all the same. There was very little communication with us which made the waiting all the more difficult. I hated having to be the one to contact the Coroner for an update rather than it being the other way around. We were his parents after all! Unfortunately our experience seems to be similar to other families we have spoken to more recently. However, at the time, I felt as though our case had to be an exception to the norm.

We decided to have Sam's body cremated and, after ten months, we felt ready to do something with the ashes. We had a special beach near home that we had taken Sam to regularly. We knew it would be a place that we would still go to as a family in the future so we decided to scatter his ashes there.



Being a public place, our friends and family would always have access to it too. We had been mindful to include our immediate families in as much as possible after his death. When you're clouded by your own hurt, it's hard to imagine anyone else's, but they had also lost. Lost their grandchild, lost their nephew, lost their cousin. Despite this we just wanted to release his ashes alone so we asked a good friend who is a photographer to capture it for us. I now love these photos and it meant we were able to share them with our closest friends and family and always have them to explain the events to Sam's future siblings.

Sam's death affected so many people. The support we received from family, friends and work colleagues was incredible. Even from people I didn't really know. There were people who seemed more hurt than I would have expected but, looking back, it is obvious that his death brought out people's own experiences with other losses. Often things I didn't know about before. This brings people together and gives us a connection like no other. I spent a lot of time with my local mothers' group with Sam, so understandably they were affected a great deal. It was hard in so many respects to continue seeing them when they still had their own children. I felt cheated, hard done by and awkward around their children. But, on the other hand, having their support outweighed the difficulty, especially down the track. After two years, I am so pleased that I pushed through and now have some close friends that share memories of the time we had with Sam and can still talk about things he would do with us and their children.

People say the death of someone close to you makes you see life differently. For me, one of the biggest things is perspective. Things that would have normally got me stressed, anxious or worried about now seem insignificant. In a way it is liberating to have a more fearless outlook and that perspective that will never make us sweat the small things. We have surely gone

Terminology explained

Sudden Infant Death Syndrome (SIDS)

This is the name given to the sudden death of an infant, under twelve months of age, which is unexpected by history and in which a thorough post mortem examination fails to demonstrate an adequate cause of death. This is another way of saying that it is not known why these babies die.

If someone dies from a known disease, the reason is obvious and publicly recognised. When an apparently healthy infant or child dies, with no obvious explanation, it can create special problems because the death cannot be understood or explained. It is not unusual to feel guilty, to try and think of something you did, or did not do, that caused your baby or child to die. This searching for a reason is normal, but it is important to understand that no blame can be or should be attached to anyone. At this time, SIDS cannot be predicted and the causes are not yet known.

For information or support contact Red Nose Grief and Loss on 1300 308 307 or visit www.rednosegriefandloss.com.au

Sudden Unexpected Death in Childhood (SUDC)

This is the sudden and unexpected death of a child over the age of 12 months, which remains unexplained after a thorough case investigation and autopsy is conducted. Like SIDS, SUDC is a diagnosis of exclusion, assigned when all known causes of death have been ruled out. Presently, SUDC cannot be predicted and/or prevented since its cause is unknown. Most SUDC deaths occur between the ages of one and three, but researchers have looked at cases of children as old as fifteen.

For information and support, you may like to visit the website of the SUDC Program - www.SUDC.org. The SUDC Program raises research funds and provides a centralised resource for information, support and advocacy. It serves families and professionals affected by the tragedy of SUDC, and promotes awareness of SUDC in communities.



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Xi Chen (Xinyi 10.09.2010 - 17.01.2012)

Rachel Watts (Iris 22.08.2004 - 25.7.2007)

Leesa Anderson (Memphis Strong 7.8.11 - 15.11.2012)

Brenda Bain (grandmother to Riley 25.11.2007 - 27.7.2009)

Georgie and Pete Keach (Sam 13.09.2010 - 22.06.2012)

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Publications available from Red Nose Grief and Loss

- *Always your child*
- *Another baby? The decision is yours*
- *Choices in arranging a child's funeral*
- *Grandparent to grandparent*
- *Stillbirth and neonatal death*
- *To family and friends: you can make a difference*
- *When relationships hurt, too*
- *What about the other kids?*

Other publications and literature are available for parents, children, health professionals and others affected by the sudden and unexpected death of a baby or child.

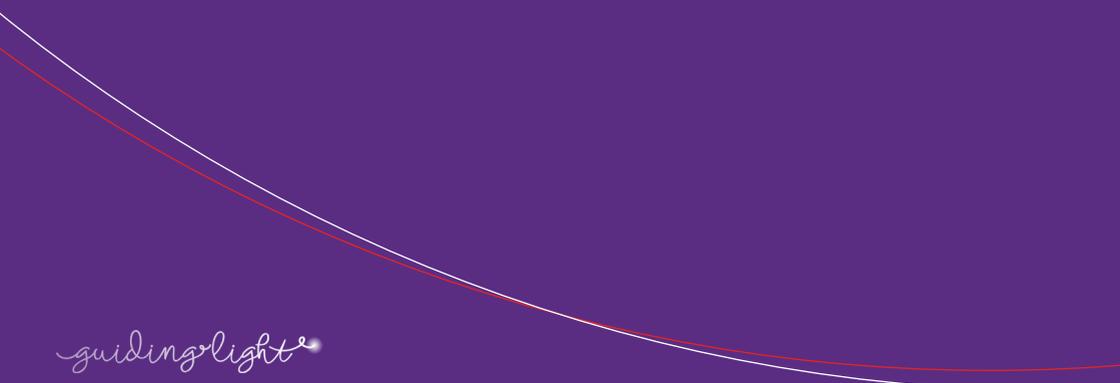
Visit www.rednosegriefandloss.com.au to access additional resources.



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