A booklet by parents whose baby or young child has died suddenly and unexpectedly.

guidinglight

To Family and Friends: You Can Make a Difference

red nose
Grief and Loss

“It’s now almost four months since Zoë died. From the dreaded morning I found her in her cot, people have been generous, courageous, considerate and, happily, their normal selves. I am thankful in my heart for all the thoughts and efforts, from the meals in the first weeks and the phone calls to see how we’re doing, to the unfussed acceptance of my crying at parties and gatherings, the remembrances of Zoë on her first birthday and the sheer bravery of just sitting with me as I go mad.

Every little bit that family and friends do is vital for us, is much-needed support. I couldn’t go on without it.”

Joanna (Zoë, 3.2.91 – 15.10.91)

Red Nose Grief and Loss formerly known as SIDS and Kids.

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Contact Red Nose Grief and Loss 1300 308 307

Introduction

Your understanding and support will make a difference

To *every* family, the sudden unexpected death of a baby or young child is devastating. The family's world is turned upside down. They may feel angry, confused, hurt – and alone. Your support, caring and friendship are so important during this time.

Death is a difficult subject, one which is frightening and unfamiliar to many people. Sometimes it is hard to know what to do or say to someone whose young child has died. You may feel awkward, uncomfortable or even afraid. But don't let your own sense of helplessness keep you away. Silence and distance can be so 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.

Three important things to know:

- People do recover from such a tragic loss eventually, but they will be changed by it and they will never forget.
- The greatest help for parents on the long road to self-healing and recovery is the understanding and support of their family and friends.
- It is easy to make a mistake or say the wrong thing in trying to support a grieving friend. But it is never too late to say you are sorry.

This booklet designed to give you some guidelines about how you can help your friend or family member – **because your help is vital**.

Straight after the death

Contact your friend or family member straight away – either visit or phone.

Make sure they know you care. A few simple words, such as *"I'm so sorry"*, or a hug, if appropriate, may be all that is needed.

Don't feel that you need to *"fix things"* – you can't. **Just be there**.

Offer some practical help, such as answering the phone and greeting visitors, preparing meals, washing, shopping or helping with the other children. **But do ask before touching any of the child's belongings**.

Encourage the parents to make their own decisions, including the difficult ones such as plans for the funeral.

Remember that *all* family members are deeply affected by the death of their baby or young child. Give your support to fathers as well as mothers.

Six or eight weeks later

Ask, *"How are you going now?"*

Listen. Be patient and listen – your friend or family member may want to go over and over what happened.

Be sensitive to your friend or family member's wish either to talk or not talk about their child.

Use the baby or young child's name and be ready to share memories.

Don't feel personally rejected by your friend or family member's extreme moods. Try another time; there will be good days and bad days.

Later on

Ask again, *"How are you going now?"*

Give your friend or family member ongoing support; parents must be able to take as much time as they need to grieve – two to three years is not uncommon.

Remember to acknowledge significant events – birthdays, anniversary of their child's death, Christmas, Mother's Day, Father's Day, etc.

Don't hesitate to send your friend or family member a letter or card telling them that you are thinking of them.

Invite your friend or family member to go out with you to do things you would normally do together. Ensure that your friend or family member does not feel isolated, but be sensitive to times when they want to be alone.

If you are unsure how your friend or family member will feel about seeing your young child or children, ask them.

Finally

Find your own way to help your friend or family member. There are many ways of showing ordinary human kindness, so do keep trying, tactfully and gently.

It's alright to show your emotions – you can be honest with your feelings.

Make sure you have support for yourself; supporting your friend may not be easy.

By reading this booklet, you are already showing that you care and want to do your best to support your friend or family member. The following pages go into more detail about how your friend or family member might be feeling, and what you can do to support them. We hope that the suggestions in this booklet will give you some confidence in your ability to be helpful.

Just being there

Why is your support necessary?

In our sophisticated Western society, many of us are not good at dealing with death, and often we feel uncomfortable and 'out of our depth' when a friend suddenly becomes traumatised and bereaved, as occurs when a child dies suddenly and unexpectedly.

Every family who experiences the sudden and unexpected death of a baby or young child will be deeply and profoundly affected, both by the loss of their child, and for many, by the *trauma* of discovering their child dead.

We know from our experience that the strength and effectiveness of the support they receive from their family and friends is the single most important thing assisting the healing process. So the support you can give *will make a difference*.

> *"1991 meant eight years later and a phone call from a friend just to say, 'It's Lachlan's anniversary Thursday, isn't it?' What a relief, as he is still remembered."* Carol (Lachlan, 21.12.82 – 23.5.83)

Making contact

Often, the first contact with a friend or family member whose baby or young child has died is the most difficult. But making this first contact is so important. Even if you are feeling awkward, uncomfortable or afraid, take a deep breath and then take the initiative. Drop by your friend or family member's house to let them know that you care. Or telephone and say something like, "*I don't know what to say, but I wanted you to know that I was thinking of you.*"

On your first visit, you will probably need to say little. Tell them you are very sorry, and that you will try to be there if they need you. Just a hug may help.

Listen, let them tell you what they are feeling, and accept this even if you do not understand it. Try not to say things like, "*I know how you feel*", or "*You must feel miserable.*"

Listening and trying to understand

One of the most important things that you can do for a friend or family member whose child has died is simply to listen. Some parents feel the need to go over and over what happened, and need someone who is willing to listen to them. Sometimes, with the best of intentions, friends or family members try to change the subject when the parents begin talking about their dead child. While you may think it will be helpful to try to get their minds off their child, it usually isn't.

Some parents feel more comfortable not talking about their dead child, but may still need someone just to be there with them. So try to accept silence too. Be aware, though, that your friend or family member may change their mind, and may want to talk about their child at some other time.

Every experience is unique, and every person experiences a unique grieving process. While their behaviour may seem strange to you – for example, if they cry constantly, even long after the death, or if they rarely, if ever, cry – try to accept it as a part of their grieving process. Do not be surprised at the things parents may do. There is no right or wrong way to grieve, and anything that comforts parents is normal. Try not to say things like, "*You ought to be feeling better by now*"- people heal in their own time.

> ***"Of all the remarks made at the time of my son's death to comfort me, my friend who said 'I cannot imagine how you must be feeling' came the closest to acknowledging my unique pain."*** Louise (Luke, 17.2.90 – 29.6.90)

Remembering

Memories of a baby or young child who has died can sometimes bring tears or anger to parents. But memories can also bring smiles. Don't avoid talking about the baby or young child out of fear of reminding the parents of their pain (they haven't forgotten!). By mentioning the child's name, and recalling his or her special, endearing qualities, you are allowing the parents to share their memories.

The child who has died can never be replaced; he or she will always be a special part of the family. So try not to say things like, "*At least you have other children*" or "*You can always have another baby.*" The other children are important, and having another child may be something the parents choose to do. But the child who has died will never be forgotten or replaced.

Support for the grieving family

Fathers grieve too

When a baby or young child dies, it is generally accepted that mothers will grieve. But it is not widely accepted that fathers will grieve, too. They will be deeply hurt, though some may not show their grief as openly as do mothers. Fathers need friendship and support; they need to be allowed to talk about their child if they wish, and they need to know that you care. In fact, they need all the same sorts of support that mothers need. Try not to say things like, *"How is your wife doing?"* without also asking how *he* is doing. Almost everything that you think to do in support of a mother whose child has died, will also be appreciated by the father.

Brothers and sisters

When a baby or young child dies, it is important to remember that the child's brothers and sisters will be grieving. They too will experience the pain of grief, but they will express it in different ways. For example, they may be unusually clinging or anxious, may have nightmares, or may **appear** unaffected. They will have questions, and their own fears.

Sometimes parents may appear uninterested in their other children for a time, or simply do not have the energy to give them the attention they need. If you can, try to give special attention to the child's brothers and sisters. This will be helpful both to the children and to the parents.

Grandparents

Grandparents will be deeply affected when a grandchild dies. They will grieve not only for the loss of their grandchild, but also for the pain their own child is suffering. Grandparents, too, will need support and comfort.

Practical matters

Sometimes it is a big help to parents if you can lend a hand with practical matters and everyday chores. Don't be afraid to ask your friend or family member if you can do something to help. Make suggestions like, "*Can I take your kids to kinder*?" or "*Would you like me to pick up some shopping*?" If you take the initiative, your friend or family member will not have to feel that he or she is imposing.

Don't be offended, though, if they refuse your help. Some parents may feel that a part of their parenting role is gone, and thus they want to continue with as many day-to-day chores as possible to reaffirm their role as parents. Some also find a sense of security in routine.

So be flexible. Offer to help, but don't insist. And if they say no at first, perhaps you can ask again at another time when they may really want some practical help.

Some of the things you can do to help.

- Washing clothes (ask before you wash any of the baby or young child's clothes).
- Washing dishes (ask before you wash any of the baby or young child's bottles or dishes).
- Tidying up around the house (but leave the nursery untouched).
- Preparing meals for the rest of the family (the parents may not want to eat much at first).
- Looking after the other children.
- Grocery shopping.
- Answering the phone and greeting visitors.
- Making phone calls that may be difficult for your friend or family member, such as notifying distant relatives or notifying Centrelink regarding Family Allowance.
- Helping to answer correspondence.
- Driving your friend or family member to places they need to go.
- Mowing the lawn or taking care of the garden.
- Feeding the pets.

> *Not long after Franklin died I came home to find someone had left a cake at the door. This meant that someone had thought of us and had acted upon this."* Erica (Franklin, 10.2.89 – 21.7.89)

Making decisions

After the death of a child, some parents feel inadequate or helpless. It is tempting to want to make decisions for them, so that they do not have to worry. But if you take over their decision-making, you may inadvertently make them feel even more helpless. Many parents have said that they wished they had taken a more active part in their baby or young child's funeral, for example. Even if you do not agree with their decisions, try to accept them as the right ones for the parents at that time.

In addition to funeral arrangements, the decision of if and when to put away the baby or young child's clothing, pictures and toys must be that of the parents. They need to decide what to do with these things in their own time. Sometimes the father and mother do not agree; it is important that you do not take sides, but try to understand how each person feels.

If the parents are feeling overwhelmed or frustrated, try to encourage them to be patient with themselves and not to expect too much of themselves. If you are there for them, they may feel more capable just knowing that someone cares and will help if needed.

Keeping in touch

As time goes on, family and friends may be less available, but the parents may still need support. Grieving is not a "process" that will be finished in a matter of months; each parent's experience will be unique, and they must be able to take as much time as they need to grieve. Sometimes significant events, such as the baby or young child's birthday, the anniversary of his or her death, Christmas, and Mother's and Father's Day, and the week or weeks preceding these events, will be particularly difficult for the parents. Many parents find it comforting when friends and family remember these special days.

“Franklin’s first birthday anniversary aroused a great deal of mixed feelings. He had died six and a half months earlier. The two cards received, one from my sister and one from my mother, touched me to the bottom of my heart. At least someone had remembered that he was even born!” Erica (Franklin, 10.2.89 – 21.7.89)

Some special issues

Guilt and self-blame

In some circumstances of death, parents may blame themselves for the death of their child. Listen to them without making any judgements. You might try to reassure them that what happened was not their intention. You might speak about their loving care for their child and whatever else you know to be true and positive about their devotion to their baby or young child. But be prepared to listen to their doubts and fears as well.

With Sudden Infant Death Syndrome (SIDS), the causes are still not known. We have learned over the years, though, that there are some things that do *not* cause SIDS. Many parents feel responsible in some way for the death of their baby or young child. They mistakenly believe that something they did, or did not do, or even their ignorance or neglect, somehow contributed to the death. Although this is a natural reaction, any such guilt is unfounded.

Other children of similar age

If you have a baby or young child about the same age as the child who died, ask your friend or family member how they feel about seeing your child. Some may want to cuddle and nurse your child, while others may not want to see a child at all. If they do not want to see your baby or young child at one particular time, understand that they may change their mind later.

Their first child

When a first or only child dies, parents suddenly lose their identity as a family. This can be very hurtful. While their *parenting role* is gone, they will never stop being a *parent*. Their child will always be a part of their family.

Take care of yourself

Giving support to your friend or family member means sharing their pain. Listening and caring can be exhausting. So make sure you have support for yourself.

> *We had looked forward to our first Christmas as a family, but this was not to be, because Zoë died mid-October at eight and a half months. We received dozens of Christmas cards, but the one that meant the most to me was the only one to mention our daughter. It simply said "...and our memories of Zoë remain clear." I was so grateful that her life was acknowledged, and that someone had thought to let us know that she hadn't been forgotten."* Joanna (Zoë, 3.2.91 -15.10.91)

Each experience of a child's sudden and unexpected death is unique, and parents react in very different ways to their own tragedy. No matter what the experience, though, they will need friendship and support. Your friend or family member will never forget their loss, but they will eventually learn to live with it. And while your lasting support and friendship will not take away the pain, it will make it more bearable.

You may never know the value of the support you have given, but you *will* make a difference.

“Then there are those, the blessed ones,
who say in so many ways
the only thing I need to hear.
“I am so sorry David.”
“I am with you David.”
The ones who, even five weeks later,
ask gently, as if for the first time:
“How are you today?”
“How are you doing now?”
These bring tears to my eyes.
These you could not buy with gold.”

From the poem entitled “Michael” By David Morawetz

(Michael, 4.3.85 – 18.4.85)

(Published in the United Sates as “Go Gently – A Parent’s Grief” Centering Corporation 1991)

Other Support

Suggested reading

A range of books, newsletters, research and articles on grief, tapes, brochures, and videos, are available from Red Nose Grief and Loss. Subjects covered include factual information about the sudden and unexpected death of a child, SIDS, the impact of the sudden death of a child on the family and the community, how to cope with children's reactions, having another baby or young child, research and various support services. *See page 20 for listing.*

Other support organisations

For further assistance, you might like to look up the following associations:

The Compassionate Friends (for those who survive their child/ren).

SANDS Australia (Stillbirth And Neonatal Death Support).

NALAG (National Association for Loss and Grief).

Acknowledgements

The material contained in this booklet comes from parents who have had a baby or young child die. These parents wanted to stress the importance of the support they received or wished they had received. We gratefully acknowledge their contribution.

Anne Giljohann, Red Nose Grief and Loss (formerly SIDS and Kids Victoria)

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*

— *When relationships hurt, too*

— *What about the other kids?*

— *Your child has died: some answers to your questions*

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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