

For family
and friends



First edition © Sands 2014

No part of this booklet may be reproduced in whole or part, in any form or by any electronic or mechanical means without the prior written permission of Sands. All rights reserved.

Whilst every care is taken in providing information, please note that it is of a general nature and that readers should seek professional or expert advice as appropriate to their specific circumstance. Sands does not accept any liability, including liability for any errors or omissions.

All information is correct at the time of going to print: March 2014.

Sands

3rd Floor
28 Portland Place
London, W1B 1LY

t: 020 7436 7940
e: info@uk-sands.org
w: www.uk-sands.org

Helpline 020 7436 5881 helpline@uk-sands.org

Sands message boards www.sandsforum.org

Sands publications 0845 6520 445 or order online at shop-sands.org/shop

Registered as a charity in England and Wales (299679) and in Scotland (SC042789)

Text written by Judith Schott and Alix Henley, 2014

We are grateful to the many parents, family members and friends who have contributed to this booklet.



“When I can talk about my daughter, say her name, talk about the agony and ecstasy of her little life, I feel a deep relief. Those people who want to hear, who don’t flinch when I say her name, who smile and look me in the eyes and ask me how I am and really care about the answer, those are my true friends.” Mum



Contents

Introduction	06
Getting the news – how you might feel	07
Understanding grief	08
When a baby dies	08
The experience of grief	09
Grief and partners	11
Grief and children	11
What to say	12
Things that may help	14
Offering support	16
Offering practical help	17
If the parents already have a child or children	19
Other people’s pregnancies and births	20
When relationships are difficult	21
The longer term	22
As time goes by	22
Another pregnancy?	23
Getting support for yourself	24
Useful addresses	25
How Sands can help	26
Sands support resources	27

Introduction

This booklet has been written for family members, friends and colleagues who are affected when a baby dies before, during or after birth. We hope that you will find it helpful. You may also want to read some of our other support booklets. You will find a list on page 27.

Getting the news - how you might feel

Hearing that a baby has died before, during or after birth is always shocking. It is especially devastating when it happens to a family member or to someone you are close to.

"I had seen my friend the day before - everything was fine and it didn't occur to me that anything could go wrong. When I heard that her baby had died shortly after birth I was very upset and sad. But my overriding feeling was fear. I never knew this could happen. Nothing that horrendous had happened to anyone we know. I realised it would have a massive effect on everyone." Friend

If either parent phones you to tell you that their baby has died, try not to ask a lot of questions – remember that they are likely to be extremely shocked and distressed and may have other calls to make. It's also important to recognise that, however awful the news makes you feel, the last thing a parent needs is to feel obliged to support anyone else.

If you get the news via text or email, or if you hear the news from someone other than the parents, you will be able to take some time to think about what to do and what to say.

"Because people have 'time' to be shocked and compose a reply, some of the most touching messages came from these emails." Dad

Many parents collect and treasure any keepsakes that confirm their baby's existence. Supportive and caring messages can be part of their collection. So, whether or not you have already spoken to the parents, you could send them a text, an email, a card or some flowers, just to let them know how sad you are to hear their news, that you are thinking of them and are there for them if they need you.

Understanding grief

This section is about the grief that bereaved parents are likely to experience and also about grief in general. We hope you will find it helpful.

When a baby dies

The death of a baby before, during or after birth is a major bereavement. Although every parent is an individual and circumstances may differ, the grief that follows the death of a baby is likely to last for many months and even years. It never goes away completely, but eventually most parents reach what some call “a new normal.”

Some people assume that a loss during pregnancy, especially if it’s early on, is not as devastating as the death of a baby at or after birth. However, the stage a pregnancy has reached does not predict the length or depth of a parent’s grief. Parents who lose a baby at any stage of pregnancy may experience the same overwhelming grief as those whose baby dies around the time of birth or later.

Parents grieve not only for their baby but also for their lost hopes and dreams and for the future they had planned. Seeing other children at the ages and stages that their baby would have reached if he or she had lived can be a life-long, painful reminder for parents of what might have been, and may trigger renewed waves of grief.

“The pain is still deep inside, surfacing occasionally, but you get through somehow. You have to. I still cry, with some days being better than others. Seeing other mothers passing with toddlers her age and imagining what she would look like, it always brings a tear or two so I have to turn away.” Mum

Many people assume that if the parents have a surviving twin or more babies from a multiple birth, already have one or more children, or could have more children in the future, they will not feel the loss so deeply. But each baby is unique and cannot be replaced.

“It was really hard and confusing – grieving for our beautiful baby son and at the same time feeling so relieved and delighted to have his twin – our wonderful baby daughter.” Mum

The experience of grief

If you have been bereaved yourself, you will know that it’s common to feel shocked and numb, especially at first. People may experience a whole range of other feelings, including profound sadness, often accompanied by crying and sobbing, restlessness, anger, guilt, depression and also loss of confidence and self-esteem. These feelings don’t come in any particular order; they are unpredictable and come in waves.

People who are grieving may also have physical symptoms such as difficulty sleeping, and changed eating patterns. They may sigh a lot or feel a heavy weight on their chest or butterflies in their stomach.

If you are close to the parents, you too may be grieving for the baby and may experience some of the same feelings.

“I found myself feeling very angry. Why did this happen? Then I felt guilty about feeling so angry. Looking back, I realise that feelings like this are a normal part of grief and nothing to feel bad about.” Mum’s brother

The parents' loss may also be a painful reminder of losses that you have experienced. This can be very hard to deal with and you may need to get some help and support for yourself. Some bereaved parents say that they end up supporting distressed family members and friends rather than the other way round.

Although everyone who is grieving experiences similar feelings, the way in which each of us expresses our grief varies enormously. Some people express their feelings very openly and need to cry, talk and tell their story over and over again. Others are more contained and prefer to try to carry on as usual.

Our culture and religion influence the way we express grief. People of different generations may have different ways of dealing with grief. Men and women also tend to express grief differently. Although it's a generalisation, women may be more inclined to focus on and express their feelings than men. Some men express their grief openly; others may grieve privately. Some fathers put their grief on hold for a while and concentrate on supporting their partner and on the practical things that need to be done. Their feelings may emerge weeks or even months later. This is not necessarily a choice, just the pattern that their grief takes.

There is no right or wrong way to grieve: each of us tends to grieve in the way we were brought up to grieve, and each of us deals with grief in our own way.

Grief and partners

"It took a long time for someone to ask me how I was." Dad

There is a tendency for everyone to focus on the grieving mother and to forget that her partner is grieving as well. Partners themselves also often focus on caring for the mother and may set aside their own grief to try to stay strong and brave for her. However, it's important to remember that, whether or not they show their feelings or talk about their grief, partners are profoundly affected by the death of their baby and need support in their own right.

"Nobody is strong enough to carry two people's grief." Dad

Partners need to know that family members and friends care about how they are and how they are coping. So remember to ask how they are doing and if there is any way you could help. For more on what you can offer grieving parents, see pages 16-20.

Grief and children

If the bereaved parents already have a child or children, they will have to find ways of telling them what has happened, and why the grown-ups are very sad. They will also be dealing with their child's reactions. Even if they are too young to understand what has happened, very young children will still react to changes in the people close to them.

If you have your own child or children, you too may need to explain to them what has happened and why everyone is sad at the moment. You may find it helpful to read our booklet *Supporting children when a baby has died*.

What to say

"I really worried about what to say to her. I gave her space at first but looking back, I wish I'd done more." Close friend

Bereaved parents need to know that you care about them and that you are there if they need you. What you say and do can make a big difference, even if this is not obvious to you at the time.

"I remember the way my father-in-law reacted, jumping into his car as soon as he heard. I'll remember that to the day I die, and if he never does anything positive again, I'll always be grateful for what he did." Mum

Unfortunately, there is nothing you can say to the parents that will make things better, but there are things that many bereaved parents find unhelpful and distressing.

Here are some examples of things to avoid:

However well meant, anything that is intended to reassure bereaved parents is likely to be unhelpful.

- ▶ Avoid saying anything that implies that a baby is replaceable. For example, “You are young, you can always have another baby;” or, “At least one of the twins survived”. Each baby is an individual, and having another now or in the future cannot possibly compensate for the baby who died.
- ▶ Unless you too have had a baby who died around the time of birth, avoid saying, “I know how you feel.”
- ▶ Avoid saying anything religious, such as, “The baby is with God now;” or, “God has sent this to test you;” or, “God loves your child so much that He wants your baby to be with Him;” unless you are absolutely certain that the parents share your beliefs. Even if they do, remember that their faith may have been shaken by their baby’s death and comments such as these may add to their pain and distress.
- ▶ *“I am fed up with people telling me that this is God’s will - it isn’t... how could God do this?” Mum*
- ▶ Any sentence that begins with “At least...” is likely to be unhelpful; for example, “At least you already have a child.”
- ▶ Other statements that are intended to be comforting such as, “You will get over it soon”, or, “It was probably for the best” are also likely to be unhelpful and distressing, even if the outlook for the baby would have been poor if he or she had survived.

Things that may help

Although there are quite a few things not to say, there is nothing that is guaranteed to be right for everyone. This can be hard, as many people are naturally frightened of making things worse. But the worst thing you can do is to avoid making contact.

"A few weeks after my daughter died, a neighbour, who I thought was a friend, saw me walking up the street towards her, and immediately ducked her head down and scurried across the road to the other side, as if she hadn't seen me. But I knew she had. I felt crushed, lonely, isolated, bereft. I felt like I was a leper, or that people thought that they could 'catch' losing a baby from me." Mum

Most parents will appreciate a card, email or text to say how sorry you are. This also makes it a bit easier when you see them later. If you meet the parents unexpectedly, you could simply say, "I am so sorry to hear about your baby," or, "I don't know what to say, except I am so sorry," or, "I can't imagine how you are feeling." If you know the person well enough and think it would be acceptable, you could use gentle touch on an arm or offer a hug.

"My closest male friend John...gave me what I can only describe as a kind of hug only fathers give their sons. I will be forever indebted to him. For that moment he could not change the pain but he carried some of it for just long enough when I could not." Dad

However, a hug may not be welcome if you are in a public place, because the physical support of a hug can release tears. Crying is a good way to release tension and grief but, while this might be fine in private, some people want to avoid crying in public.

If you visit the parents or spend time with them, you could ask them to tell you about their baby. Many parents are longing to talk about their baby and what happened. Some may want to show you photographs or other keepsakes that they have collected. Some may want to tell you what happened over and over again. So probably the most helpful things you can do are just to listen, to try not to feel responsible or get upset if they cry, and to use the baby's name if one was given.

"There are a few wonderfully patient people I can talk to again and again about my precious baby and how I feel." Mum

Grief sometimes makes people behave in ways that they wouldn't normally. If you get a reaction that you don't expect or don't know how to deal with, try not to take it personally. Because grief comes in waves and can be triggered by almost anything, neither you nor the grieving parents can predict how they might react at any given moment.

"My daughter and I have always got on well. But she became really unpredictable when the baby died. I couldn't say or do anything right." Grandmother

The most important thing is to try and show the parents that you care. And if your approaches are not well received, at least you know you have done your best.

"I used to pop in a lot, but when her son died I didn't know what to do. I eventually plucked up courage and went round there and it was OK. We sat and chatted and she cried and gave me a big hug when I left." Friend

It's also important to remember that you too may need support. It's hard to see a relative or a friend suffering and be unable to help. Sands is there to support anyone affected by the death of a baby, including family members and friends. You are welcome to call or email our Helpline.

Offering support

“Holding my cousin’s baby broke my heart. His eyes were closed as if he was asleep. But I knew he would never open them. He was beautiful and perfect so how could this have happened? I felt so helpless because no matter how bad I felt, it was only a fraction of what my cousin and his wife were feeling. How could I possibly say or do anything to help them?” Dad’s cousin

It can be very difficult to find the right balance between being supportive and being intrusive. Some parents need time and privacy and want to work things out on their own. Others may be grateful to have someone who is prepared simply to spend time with them and to listen if they want to talk. It can be hurtful if people refuse some or all of your offers of help, or want to be alone. However, they need to do what feels right for them at this very distressing time.

It can also be hard to show bereaved parents that you care without burdening them with your own thoughts and feelings. Family and friends sometimes say that they feel that they are walking through a minefield. The most helpful things you can do are to let them know that you care, and to listen and accept how they are feeling without making judgements or offering suggestions or solutions. Try not to assume what will or will not help the parents. Instead, take your cue from them.

Although not everyone wants or finds it helpful to cry, crying is a good way for some people to release pent-up feelings. If someone cries, the best thing you can do is just to sit with him or her. This is easier said than done: many of us are uncomfortable when someone cries. If you find yourself shedding a few tears as well, try not to worry. Parents often say that other people’s tears help them to feel that others care. They take comfort from seeing that their baby has touched someone else’s heart.

However, it's important that you have your own sources of support, so that the parents don't feel that they have to comfort you.

Offering practical help

Depending on your situation, you may be able to offer some practical help or just some company.

"I found it very hard to get out of the flat. A kind friend offered to go with me and we walked to the park and back. It did help." Mum

In the early days and weeks, many bereaved parents find it extremely difficult to do everyday routine things such as cooking, housework, shopping or walking the dog. The parents may welcome help with some of these. However, they may also value their privacy. So if, for example, you cook a meal, check with them whether they might prefer you to take it round and then leave.

After some weeks or months, and if you share an interest such as playing a sport, singing in a choir, or going to a football match, you could suggest going together. If the parent is worried about how people there will react, you could ask if there is something they would like you to say to everyone beforehand in order to make things easier.

Some relatives and friends try to protect parents from further pain by clearing away the equipment and clothes that were bought for the baby. However, it's always important to check carefully whether this would actually be helpful. Many parents prefer to clear away the baby's things themselves, even though it may be weeks or months before they feel able to.

If you live far away, it may be difficult or impossible to offer practical help or even a hug or a shoulder to cry on. It's very hard to know that a family member or friend is suffering when you can't be there with them. You may want to show your love and support by phone or texts, online, or in cards and letters. Just letting parents know that you are thinking of them at this difficult time will make a huge difference.

Some bereaved parents prefer to talk about what has happened to other parents who have had similar experiences. The comfort of being able to say exactly how they feel to people who have been through similar experiences, and of being completely accepted and understood, is invaluable. It helps them not to feel so alone. So try not to feel hurt if they don't talk to you about how they are feeling.

If the parents already have a child or children

Even babies and very young children are sensitive to the feelings of people around them, though they may not understand what has happened. They may become clingy and dependent and their eating and sleeping patterns may change. Some may start to misbehave, wet the bed, want to go back into nappies, cry a lot or be very clingy. This can be very hard for the grieving parents to deal with.

You may be able to offer to look after their child or children from time to time, or perhaps take the children out on treats or invite them over for a playdate. Being looked after by someone they know and who cares about them can help them to feel cherished and important. However, you may need to make allowances for changes in behaviour. It's also a good idea to find out what the children have been told so that you can use the same words and phrases if they want to talk about the baby. Although many parents nowadays tell their child or children what has happened, not all do. Precisely what a child is told will also depend on the child's age and ability to understand and the questions they ask.

Other people's pregnancies and births

Even when relationships are good, it can be very hard for bereaved parents when another family member or close friend is pregnant or has a healthy baby.

"My sister-in-law announced her first pregnancy the week before the first anniversary of my baby's stillbirth. I couldn't help envying and resenting her throughout her pregnancy. Our baby should have been the first grandchild but nobody talked about her." Mum

Other people's babies and young children can be painful reminders to bereaved parents of what they have lost. Some may be happy to see and perhaps cuddle someone else's baby.

"My arms felt so empty, giving my friend's new born baby a cuddle really helped me. But I didn't want her baby, I wanted my baby back." Mum

However many bereaved parents find it distressing to be with, or to hear about, expectant or new parents and babies.

"Seeing other people's babies – it made me more desperate and I felt such a failure. Everyone else seems to do it without problems." Mum

This situation can also be difficult for expectant and new parents, who may feel constrained and unable to celebrate their baby's arrival as they would like.

"I'd just got past 20 weeks when my sister had a miscarriage. We're usually very close but since then we've had very little contact. When we do meet she'll hardly look at me and doesn't ask how I am. It's hard for my mum with one of us pregnant and the other grieving. I totally get how my sister is feeling, but it's made it hard for my partner and me to share our excitement about our own baby." Mum

Nevertheless, everyone's reactions are different, so it's important not to make any assumptions about how a bereaved parent will respond. Many say how isolated and lonely they feel, so even if you are pregnant or have a new baby, it's usually better to take a risk and offer to maintain contact rather than stay away in case you upset them.

You could, for example, send a card or text simply saying that you are thinking of them, or you could call now and then and ask how they are. You could also offer to meet. It might be helpful to ask if they would prefer to meet you on your own without your child or children.

If a bereaved parent refuses your invitations or keeps their distance, try not to take it personally. It may be the only way they can cope right now.

"The only thing I could do was be there whenever they needed me and, in time, it became easier to talk about what had happened." Dad's cousin

When relationships are difficult

Family relationships and some friendships can be complicated. Most relationships, whether with family members or with friends, come under additional strain when there is a crisis. Grief can make it harder than usual to see other people's points of view, to accept different ways of doing things, or to deal with thoughtless behaviour.

"I'll never forget the awful way my parents reacted or how my mother-in-law ignored my request for no flowers at the funeral." Mum

However, sometimes the tragedy of a baby's death puts things into perspective and makes it possible for people to set past difficulties aside and cooperate in supporting the parents.

The longer term

The emotional roller coaster that many grieving parents go through in the weeks and months after their baby has died is a natural response to their loss. This intense grief can go on for a long time; many parents find it hard to believe that they will ever feel alright again. They often feel under pressure from friends, family and colleagues to “get over” the death of their baby and move on. They may feel they have to hide their grief and try to put on a happy face. The most helpful thing you can do is not to expect too much from them too soon.

“It’s important to realise that the parents will never really get over it. Let them know that they can talk about their baby whenever they want to.” Friend

As time goes by

Most parents experience renewed waves of grief even long after their baby’s death. These may come out of the blue, or may be triggered by, for example, a song, a piece of music, or a smell. Renewed grief can also be triggered by events and dates; for example, the date the baby was due, anniversaries of his or her death, Mother’s Day, Father’s Day, family gatherings and festivals. These occasions can be especially hard for the parents. You could phone or text, or send a card, a letter or flowers, to let them know that you are thinking about them and that you too are remembering their baby.

“Two of our closest friends have sent a single yellow rose each year on our daughter’s birthday. They have never forgotten her. This means so much to us, more than they would ever realise.” Mum

Many parents and grandparents also feel waves of sadness when other children in the family, who were born around the same time, start nursery or primary school or begin to be independent. A living child's progress is inevitably a reminder of what might have been.

"The death of a grandchild is a life-changing experience. The memories never leave – but we wouldn't want them to." Grandfather

Another pregnancy?

Decisions about if and when to try for another baby are very personal and private. Some parents want to try again very quickly: others need time before they feel ready to even think about another pregnancy. Couples don't always agree about if and when they should try again. Trying again is not an option for everyone as personal or medical reasons may rule out another pregnancy. You can help by being tactful and avoiding the subject of another baby unless the parents themselves mention it.

Many people also assume that another pregnancy and the birth of a new baby will erase the parents' pain and grief. But each baby is unique. Another baby can never replace the baby who died.

All pregnancies that follow the death of a baby tend to be very stressful. Understandably, bereaved parents have lost faith in the normality of pregnancy and birth and, often, no amount of reassurance can remove the fear that this pregnancy could end in tragedy too. The birth of a new baby can also bring renewed grief because it is a poignant reminder of the baby who died.

Getting support for yourself

It is important to remember to take care of yourself and to have your own sources of support. Having a safe place where you can express your own feelings, away from the parents or others who are deeply affected by the baby's death, can help you to remain strong and supportive.

Having someone to talk to may be especially important if you are expecting a baby of your own, as knowing about things that can go wrong can be very upsetting.

"When I was pregnant myself I thought a lot about my friend's baby who died soon after birth. I found it helpful to talk about my fears." Friend

You may have a good friend whom you can talk to. You are also very welcome to call or email our Helpline for support.

Useful addresses

Other charities that can offer support

Bliss - the special care baby charity

www.bliss.org.uk

Support, advice and information for families of babies in intensive care and special care, including bereaved families.

Helpline: 0500 618 140 Email: hello@bliss.org.uk

Child Bereavement UK

www.childbereavement.org.uk

Supporting families when a child dies and when a child is bereaved.

Support and information: 01494 568 900

Email: support@childbereavementuk.org

Miscarriage Association

www.miscarriageassociation.org.uk

Support and information for those affected by pregnancy loss.

Network of support groups and telephone contacts throughout the UK.

Helpline: 01924 200 799 Email: info@miscarriageassociation.org.uk

TAMBA Bereavement Support Group

www.tamba-bsg.org.uk

Support for families who have lost one or more children from a multiple birth. (Part of the Twins and Multiple Births Association – TAMBA)

Helpline: 0800 138 0509 Email: Use the form on their website

How Sands can help

Sands is a national charity offering information and emotional support when a baby dies before, during, or shortly after birth.

17 babies are stillborn or die shortly after birth every day in the UK, and each year we support thousands of families whose babies have died.

At Sands there are people who understand what it's like, because many of us have been through this devastating experience ourselves.

You may not want anything from us right away. We are here to help whenever you feel you need it. That may be now or in a few weeks, months or even years.

As well as supporting mothers, fathers and same sex partners, we are also here to help other members of the family and the many other people who may be touched by a baby's death, including friends, colleagues and health care staff. All are welcome to contact us for support and information.

Do you want to speak to someone on our Helpline?	020 7436 5881
Do you want to email the Helpline for support?	helpline@uk-sands.org
Do you want to connect with others whose baby has died?	www.sandsforum.org
Do you want to find out about a Sands group near you?	helpline@uk-sands.org
Do you want to know about our other support booklets?	Please see page 27
Do you want to see what's on offer at our shop?	www.shop-sands.org/ shop/
Do you want to know more about what we do?	www.uk-sands.org
Do you want to make a donation or fundraise?	fundraising@uk-sands.org
Do you want to write to us?	Sands, 3rd Floor, 28 Portland Place, London, W1B 1LY

Sands support resources

If you would like more information on any of the subjects we have mentioned, please see our current list of Sands booklets below. You can read or download copies of our booklets on the Support section of our website www.uk-sands.org or you can order copies from our online shop www.shop-sands.org/shop or by calling 0845 6520 448.

Sands booklets

When a baby dies before labour begins

Saying goodbye to your baby

Deciding about a post mortem: information for parents

Mainly for fathers

Supporting children when a baby has died

Sexual relationships after the death of your baby

Information and support for grandparents

For family and friends: how you can help

Returning to work after the death of your baby

Information for employers: helping a bereaved parent return to work

Another pregnancy: for parents whose baby has died

About Sands

Sands, the stillbirth and neonatal death charity, was founded in 1978 by a small group of bereaved parents who were devastated by the death of their babies, and by the total lack of acknowledgement and understanding of the significance and impact of their loss.

Since that time, we have supported many thousands of families whose babies have died, offering emotional support, comfort and information. Today Sands operates throughout the UK and focuses on three main areas of work:

We support anyone affected by the death of a baby

Bereavement support is at the core of everything we do. Some of the services that we offer include:

- ▶ Helpline for parents, families, carers and health professionals
- ▶ UK-wide network of support groups run by trained befrienders
- ▶ Online forum and message boards enabling bereaved families to connect with others
- ▶ Website and a wide range of booklets, books and other resources.

We depend on the extraordinary energies of our supporters to raise the vital funds that we need to deliver the wide range of services that we offer.

We work in partnership with health professionals to try to ensure that bereaved parents and families receive the best possible care

We offer resources and a comprehensive programme of training, workshops and talks for health professionals that give practical guidance on how to meet parents' needs and provide good bereavement care.

We promote and fund research that could help to reduce the loss of babies' lives

The UK has one of the highest rates of perinatal death in the developed world. The shocking reality is that, in spite of medical advances, 17 babies are stillborn or die under one month old every day.

We raise vital funds for research and campaign for the government to address this situation as a matter of priority.

If you would like any further information or support please contact us or visit our website.

Support:

t: 020 7436 5881

e: helpline@uk-sands.org

Enquiries:

t: 020 7436 7940

e: info@uk-sands.org

Write to us:

3rd Floor, 28 Portland Place,
London, W1B 1LY

Website:

www.uk-sands.org

