## Information for employers

Sands Stillbirth & neonatal death charity

Helping a bereaved parent return to work





#### Fourth edition © Sands 2016

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 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 error or omission.

All information is correct at the time of going to print: May 2016.

#### Sands

Victoria Charity Centre 11 Belgrave Road London, SW1V 1RB

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 www.uk-sands.org/shop

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

Text written by Judith Schott and Alix Henley

We are grateful to the employers and parents who have contributed to this booklet.

"I was so scared of going back to work after my baby died. I had thought that the next time I went back it would be to show everyone my beautiful baby.

I didn't know how my employer and my colleagues would react or how I would cope. I felt very vulnerable." Mum

## **Contents**

#### Part 1

Grief and the workplace	06
What to say and do	07
What may help	08
What may be unhelpful	08
Discussing entitlements and benefits, and planning their return to work	09
Explaining what has happened	09
Returning to work	10
Medical appointments	11
Difficult times at work	11
Photographs	12
Part 2	
Entitlements and benefits for bereaved parents	13
If the baby was born dead before 24 completed weeks of pregnancy	14
If the baby was stillborn after 24 completed weeks of pregnancy OR if the baby was born alive at any stage of	
nreanancy and then died	15

Notes	16
More information and support	17
How Sands can help	18
Sands support resources	19
Where to get more information about rights and benefits	20
Useful addresses	22

**Part 1** of this booklet describes how a bereaved parent may feel and what he or she may find helpful. Colleagues and managers may also find it useful to read this.

Part 2 summarises the entitlements of bereaved parents at work.

We hope you will find this booklet useful. Please feel free to contact Sands if you need more information or support.

## Grief and the workplace

The death of a baby at any stage of pregnancy is devastating and is usually completely unexpected. A routine antenatal check-up may have shown that the baby's heart had stopped beating. The parents may have had to make the difficult decision to end the pregnancy because their baby had a serious abnormality.

Their baby may have died suddenly during labour. Or their baby may have been born alive but have been too ill or premature to survive. In every case the death of a baby is traumatic.

Following the death, the parents have to go home without the baby they love and have prepared for. They have to cope with telling family members and friends, decide about a post mortem, register the birth and death or the stillbirth, and plan a funeral for their baby. All these things are unimaginable to those who have not been through them.

The death of a baby at birth is also the loss of people's dreams, plans and hopes for the future. It seems to contradict the laws of nature. Bereaved parents, especially mothers, often see the death as their failure: they were not able to protect their baby. Partners may feel powerless and unable to help. Both parents' self-esteem and confidence may be badly damaged and they may feel very vulnerable. Many bereaved parents also feel isolated, cut off by their grief from the happy families they see around them.

At some point, most parents have to face the prospect of going back to work.

This may be the last thing they feel like doing. It may seem like a terrifying hurdle. While they have been living in a world of pain and sadness, other people's lives have gone on regardless. Most of their work colleagues will almost certainly have no idea what they are going through.

Because the death of a baby is often regarded as less significant than, for example, the death of an older child, many people underestimate the effect on the parents. They may expect them to "get over" the death of their baby in a few weeks or months and to "move on". But the death of a baby is a major bereavement. Although the intensity of their grief may fade over time and they may learn to live with what has happened, both the baby's mother and father are likely to be sad for a long time.

#### What to say and do

When you hear about the death of the baby, you may want to send a short note from yourself and/or colleagues, simply saying how sorry you are. If there is a funeral, you may want to send flowers or attend. Many families prefer to make a donation to a chosen charity instead of having flowers at a funeral. If work colleagues want to "do something" to express their sympathy, you may want to arrange a collection or fundraising activity in memory of the baby that has died.

Many people worry about saying the wrong thing to a bereaved parent. They may try to avoid them, or may speak to them but not mention the baby who has died. Although no one can take away the parents' grief, simple acknowledgment of their loss may help them feel less isolated.

It is important not to try to provide false comfort, diminish the significance of their baby's death, or try to "cheer up" a bereaved parent.

The box overleaf contains phrases that many parents have found helpful and also some to avoid.

#### What may help

- "I am so sorry about your loss."
- "I heard about your baby. I am so sorry. I don't know what to say."
- "Is there anything I can do to help?"

If the parents gave their baby a name, they will probably appreciate it if you use the name when you talk about him or her.

#### What may be unhelpful

- "It was fate. It was meant to be."
- "There was probably something wrong with the baby."
- It was better that he/she died." (for example, if the baby was very ill)
- ▶ "At least you can have more children. You're still young."
- "At least you have other children."
- "It could have been worse at least you never got to know him/her."
- Time will heal."

## Discussing entitlements and benefits, and planning their return to work

Grief and shock can make it hard for a bereaved employee to think clearly and be proactive. They may not feel able, for example, to get in touch with you to discuss their return to work, or to check how the death of their baby affects their entitlement to leave and benefits. It may be helpful to contact them and suggest a meeting or fix a time for a longer phone call. Part 2 of this booklet summarises entitlements for bereaved parents.

Some parents welcome the thought of the routine of work and a return to some kind of normality. For others the prospect is very daunting. In some cases an employee may ask to reduce their hours initially, or, if their job allows, to work from home. They have a legal right to have such requests considered fully and seriously.

#### **Explaining what has happened**

A bereaved employee may be worried about what to say to their colleagues when they return to work. You could suggest that they write a letter or an email explaining what has happened and saying, for example, when and how their baby died, the baby's name, weight and other details, and a simple statement about how the death has affected them and their family. This can ease the employee's first contact with colleagues and can make it easier for other people to be supportive. If the employee prefers, you could undertake to speak to their immediate colleagues and/or significant clients.

#### **Returning to work**

Grief is a very private and individual experience: each person reacts and deals with it differently. Some parents may want to talk about their baby at work; others will not. Men and women tend to express grief in different ways. Culture may also play a part: in some cultures open grieving is the norm; in others people are expected to hide their emotions and put on a brave face. An employee's response may also depend on whether they have come back to work soon after the death of their baby or have had quite a lot of time off.

Grief tends to come in waves, often unexpectedly. An employee may appear to be coping well and then suddenly find themself in tears. This is the normal ebb and flow of grief. Sands receives many phone calls from people in tears at work. Sometimes a parent just needs to talk to someone who will listen, and can get back to work afterwards. Try to reassure them that it is all right to take a little time away from the immediate workplace. They may find it helpful to speak to a colleague, phone a family member, or phone our Helpline (see How Sands can help on page 17). If possible, make a phone available for them somewhere private.

Some temporary effects of profound grief include exhaustion, inability to sleep, and difficulty in concentrating or feeling motivated. If possible, try to welcome the employee back with the agreement that they will do "as good a job as they can" for the first few weeks. Simply recognising and acknowledging their situation can, in itself, ease some of the pressure and anxiety that many bereaved parents feel about being back at work.

#### **Medical appointments**

Parents often need to attend medical appointments after the death of a baby. The mother usually has a six-week follow-up appointment. Her partner may also want to attend. Both parents may have a hospital appointment to discuss post mortem results. Some may need to see a genetic counsellor to discuss risks in future pregnancies. If at all possible, they should be given leave to attend these important appointments.

#### Difficult times at work

The acute grief that follows the death of a baby may last for many weeks and months. At some point the intensity of the grief will fade, but an event or an anniversary or, for example, the news that a colleague is pregnant, can reawaken a parent's grief.

Certain dates, for example the baby's due date and the anniversary of the death, can be especially sad and difficult. Some parents may ask for a day off on these dates. Other days that celebrate parenthood, such as Mother's Day and Father's Day, as well as Christmas and other festivals, can be very hard.

If the mother becomes pregnant again, both parents are likely to feel heightened anxiety, stress and conflicting emotions. Other people may find this difficult to understand: they often assume that a bereaved parent must be happy to be having another baby. But a new baby will not replace the baby who has died, and many bereaved parents are hurt if other people assume that it could. Each baby is an individual with a permanent place in their hearts.

Many parents are also terrified that this baby will also die.

#### **Photographs**

For many bereaved parents, a photograph of their baby is their most precious possession which they may want to display on their desk or in their locker. Although most babies who have died look normal, some people, especially pregnant women and expectant fathers, may be distressed by being reminded that not all babies are born healthy and alive. It is worth bearing in mind that bereaved parents may be equally upset by seeing family photos with healthy babies on other people's desks or lockers. Although photographs can be a sensitive issue, it is important that people are allowed to display them.

# Entitlements and benefits for bereaved parents

Entitlements and benefits are complicated and depend on different factors such as length of employment and level of earnings before the birth. They also change frequently.

For a downloadable booklet giving more details on up-to-date entitlements, go to the HMRC website: www.hmrc.gov.uk and search for the current version of the Employer Helpbook for Statutory Maternity Pay. (Also called Employer Helpbook E15).

The Money Advice Service has a leaflet on benefits specially for bereaved parents: Late miscarriage, stillbirth, neonatal death – A guide to the financial help available. A copy can be obtained from the Sands Shop or Helpline (see page 17).

## If the baby was born dead before 24 completed weeks of pregnancy

The grief and shock of losing a baby after 14 or 16 weeks of pregnancy can be much the same as following a stillbirth. But for legal purposes, a loss at any stage before 24 completed weeks of pregnancy is called a miscarriage.

This can be very hard for parents who want their baby and their loss to be officially recognised. There is no entitlement to Maternity or Paternity Leave following a miscarriage.

A bereaved parent who is unable to go back to work for medical reasons qualifies for Sick Leave, provided they have a note from their GP. Sick Leave taken by a woman immediately after a miscarriage is likely to be "protected" in the same way as other pregnancy-related illness. (That is, she should not lose out because of her absence from work.) It is good employment practice to record this separately from other Sick Leave, in order to make sure that the woman cannot be regarded as having been treated unfavourably because of the miscarriage. However, if an absence continues for a long time, it may be arguable that it is no longer pregnancy-related. If a bereaved mother is normally entitled to sick pay from your organisation, she is also entitled to Sick Pay for pregnancy-related Sick Leave.

If an employee is not sick but needs time off, consider allowing them Compassionate Leave or Time Off for Dependants (TOFD). Alternatively, they can ask for paid or unpaid leave.

## If the baby was stillborn after 24 completed weeks of pregnancy OR if the baby was born alive at any stage of pregnancy and then died

**The mother** is entitled to 52 weeks' Maternity Leave. She should normally have informed your organisation that she was pregnant before the 24th completed week of her pregnancy. If her baby was born alive before 24 completed weeks and then died, she is still entitled to 52 weeks' Maternity Leave even if she had not yet informed your organisation.

The mother may also be entitled to Statutory Maternity Pay (SMP), depending on her level of earnings.

**The father or partner** may be entitled to one or two consecutive weeks' Paternity Leave, depending on how long he has worked for your organisation. He should normally have informed your organisation that his partner was pregnant before the 24th completed week of her pregnancy. If the baby was born alive before 24 completed weeks and then died, he is still entitled to Paternity Leave even if he had not yet informed your organisation.

The father may also be entitled to Statutory Paternity Pay (SPP), depending on his level of earnings and other factors.

A mother's female partner has the same entitlements to leave and pay as a father.

**Both parents** If a bereaved parent who is not on Maternity or Paternity Leave is unable to return to work for medical reasons, they qualify for Sick Leave, provided they have a note from their GP. If an employee is not sick but needs time off, consider allowing them Compassionate Leave or Time Off for Dependants (TOFD). Alternatively, they can ask for paid or unpaid leave.

## **Notes**

## More information and support

Sands has a wide range of support services available for parents, other members of the family, grandparents, and other children. Many people 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.

The following pages include further details of Sands support resources and contact details of other charities and organisations that may be helpful to you following the death of your baby.

## How Sands can help

Sands is a national charity offering information and emotional support when a baby dies before, during, or shortly after birth. We support anyone affected by the death of a baby for as long as it's needed.

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 helpline@uk-sands.org Do you want to email the Helpline for support? 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 19 Do you want to see what's available at our shop? www.uk-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 Victoria Charity Centre 11 Belgrave Road

London, SW1V 1RB

#### **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.uk-sands.org/shop or by calling 0845 6520 445.

#### Sands booklets

When a baby dies before labour begins

Saying goodbye to your baby

Deciding about a post mortem: information for parents

Deciding about a funeral for your baby

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? After a late miscarriage, stillbirth or neonatal death

Long ago bereaved

# Where to get more information about rights and benefits

## Money Advice Service www.moneyadviceservice.org.uk

For up-to-date summary of financial benefits. In the "Search the site" box enter one of the following phrases: "Late Miscarriage / Stillborn / Died shortly after birth"

#### **Government websites**

These UK government websites contain more detailed information about the different benefits to which parents may be entitled and how to claim them, as well as links to downloadable claim forms, email addresses, telephone numbers etc.

England, Wales, Scotland: www.gov.uk Select Benefits

Northern Ireland: www.nidirect.gov.uk Select Money, tax and benefits

Enter what you are looking for into the search box at the top of the page and click on *Go*.

For most benefits parents can also phone or visit your local Jobcentre or Jobcentre Plus (in Northern Ireland: Jobs and Benefits Office, or Social Security Office).

#### For more help and advice on employment or financial issues:

#### **Working Families**

#### www.workingfamilies.org.uk

A campaigning charity which supports and gives a voice to working parents. Gives financial and other advice over the phone or by email.

Helpline: 0300 012 0312 Email: advice@workingfamilies.org.uk

#### **ACAS**

#### www.acas.org.uk

Acas provides free and impartial advice for employers, employees and representatives on a range of employment relations and employment rights.

Helpline: 0300 123 1100

## Useful addresses

#### Other charities that offer support

#### ARC

#### www.arc-uk.org

Support for parents who experience a late miscarriage or loss after 24 weeks following a diagnosis of fetal anomaly (parents who continue with the pregnancy and those who end the pregnancy).

Helpline: 0845 077 2290 or 0207 713 7486 via mobile

Email: info@arc-uk.org

## 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 in situations of loss and for future pregnancies.

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

#### **Child Bereavement UK**

#### www.childbereavement.org.uk

Supporting families when a baby or child dies and when a child is bereaved, including support in another pregnancy.

Support and information: Freephone 0800 02 888 40 or 01494 568900

Email: support@childbereavementuk.org

#### **Miscarriage Association**

#### www.miscarriageassociation.org.uk

Support and information for those affected by pregnancy loss, including help during another pregnancy.

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.org.uk/bsg

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

Helpline: 0800 138 0509 Email: use the form on the website

#### Winston's Wish

#### www.winstonswish.org.uk

Help and support for bereaved children and young people up to the age of 18.

Helpline: 0845 203 0405 Email: info@winstonswish.org.uk

#### Other useful addresses

### Baby Mailing Preference Service (MPS)

www.mpsonline.org.uk/bmpsr

Free site where you can register online to stop or reduce baby-related mailings of samples, advertisements etc.

Address: DMA House, 70 Margaret Street, London, W1W 8SS

Tel: 020 7291 3310 Email: bmps@dma.org.uk

## **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 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.

We believe many babies' deaths could be prevented with better care and information. We raise vital funds for research to understand why babies die and how to save lives. We also campaign to make addressing the tragedy of too many baby deaths a government priority nationally.

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.

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:

Victoria Charity Centre 11 Belgrave Road London, SW1V 1RB

#### Website:

www.uk-sands.org

