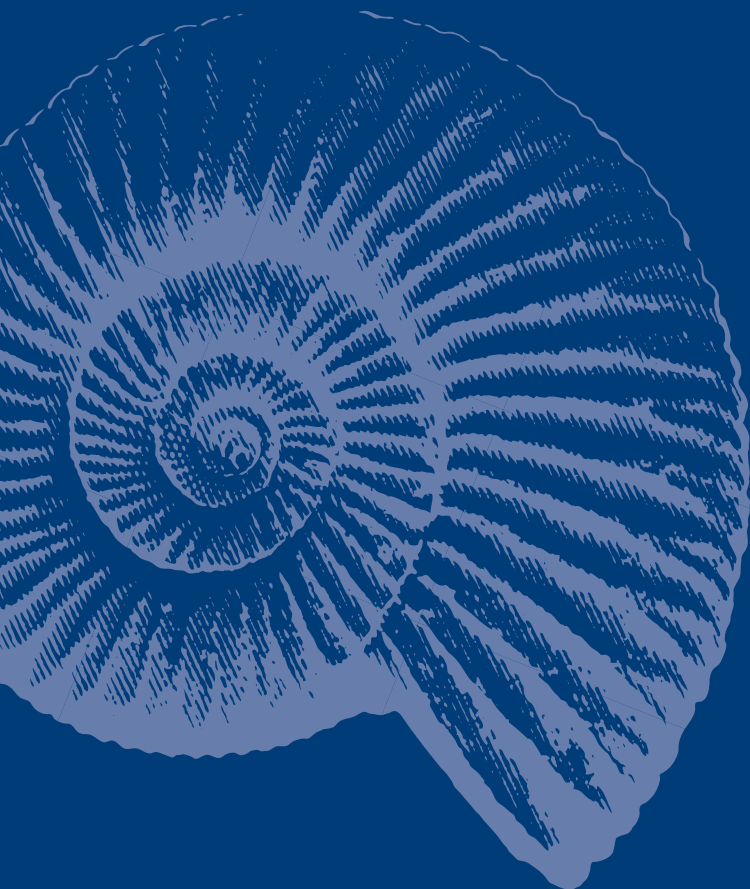


Long ago bereaved



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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

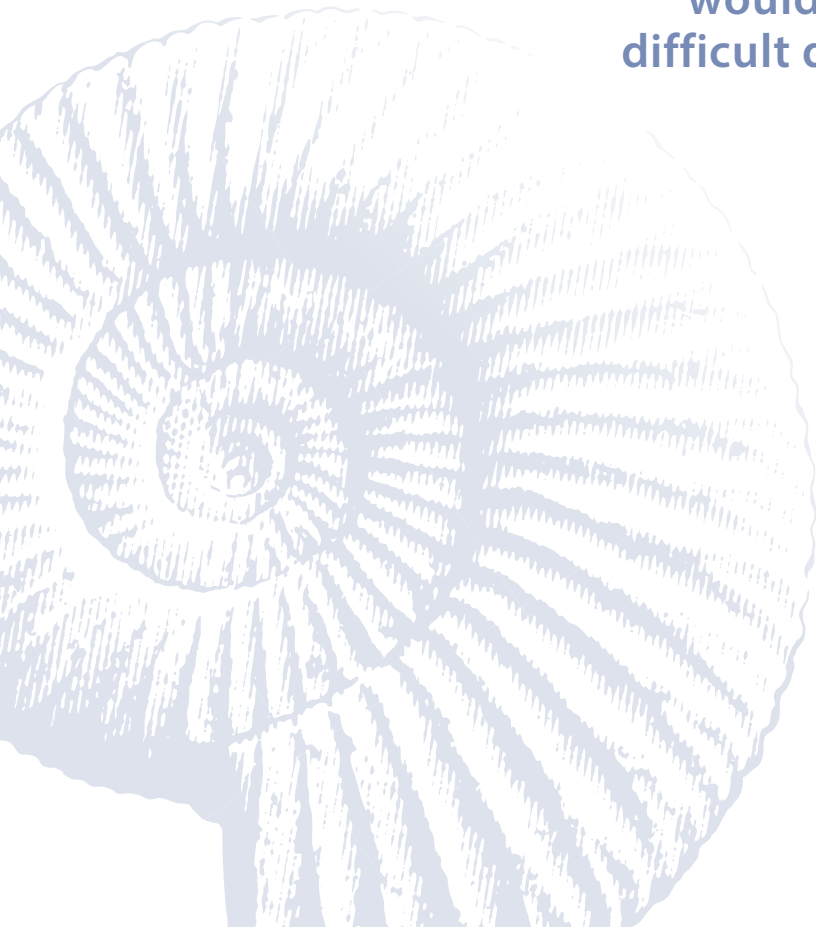
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Text written by Judith Schott and Alix Henley, 2014

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



“If only we had known that what we were feeling was normal. It would have been helpful to know that the grief never goes away completely and that the anniversaries of our baby’s death would always be difficult days.” Mum



Contents

Long ago bereaved	05
How attitudes and practises have changed	06
Stillbirth, birth and death certificates	11
Tracing a baby's grave or record of cremation	12
“Late miscarriages”	12
Stillborn babies and babies who died after birth	13
Where to start	14
If you find the cemetery or crematorium	16
What you could do to commemorate your baby	18
Visit a memorial garden	18
Come to a Lights of Love service	20
Arrange a ceremony to commemorate your baby	21
Other things you might like to do	22
How Sands can help	24
Sands support resources	25
Useful addresses	26
Other charities that can offer support	26
Other useful addresses	27
UK National Register Offices	28
Notes	30

Long ago bereaved

The death of a baby around the time of birth is a major bereavement which can have life-long effects on parents and their families. So it's not surprising that Sands is often contacted by parents whose baby died many years ago, and who now want to talk about what happened and how they feel.

It's perfectly normal for sadness and grief to re-emerge many years later. Sometimes a TV or radio programme or an article prompts a parent to call. Sometimes it's a family event, such as the youngest child leaving home, the arrival of a grandchild, a serious illness, or another death. And sometimes parents feel impelled to call us out of the blue and for no obvious reason.

Many parents want to know that they are not alone and that others share their feelings. For some, this may be the first time they have felt able to talk about their baby and to express their grief. Some parents want to discuss ways in which they could commemorate their baby, or to find out what happened to their baby's body.

We are also contacted by surviving brothers and sisters and other family members who would like to find out more about the baby and about what happened at the time. This may be because the parents have asked them to find out, or because the parents have never felt able to talk about what happened and close family members now want to know.

We welcome all calls and emails from anyone who is affected by a baby's death, however long ago it happened, and we hope that you will find this booklet helpful.

How attitudes and practices have changed

“Don’t you fret – you just concentrate on getting better. We’ll take care of everything. What you haven’t had you’ll never miss. Just remember, dear, that you’re so lucky. You have three wonderful children at home.” Advice given to a newly bereaved mother in 1978

It was only in the mid-1980s that the death of a baby around the time of birth began to be recognised as a major bereavement. Until then, a baby who was born dead at any gestation was swiftly removed from the labour ward: the parents were given no opportunity to see or hold their baby.

“When they rushed my baby out of the room, I assumed I’d given birth to a monster, something that was too awful to look at. That thought haunted me for many years. Now I realise that he probably looked perfect, just as if he was asleep.” Mum

Some mothers were sedated after the birth because it was thought that this would help them forget. There was a general belief, both amongst professionals and society as a whole, that parents could, and should, forget their babies, and that it was best to carry on as though nothing had happened. Expressions of grief were discouraged.

“When we wanted to talk about how we felt or express our grief, we were told not to dwell on things. So we just had to bottle them up and try to get on with our lives.” Mum

Before the 1970s, fathers were assumed to be fairly detached from their partners' pregnancies and most were excluded from the labour ward. It was only in the 1970s that fathers began to stay with their partners during labour. Even then they were tolerated, rather than welcomed as fathers with their own needs. When a baby died, the father's feelings were usually ignored. He was expected to be strong and self-contained, and to focus solely on supporting the mother. Bereaved fathers were often told to encourage their partner to forget the baby who had died and to have another baby as soon as possible.

"Our baby daughters were stillborn in 1977, 1979 and 1981. My husband only 'came out' as a bereaved parent in 2007." Mum

In order to "protect" bereaved mothers, fathers were also often expected to take any decisions that had to be made. If, later on, there was regret about what was decided, many fathers felt responsible and blamed themselves.

All this meant that most mothers and fathers grieved in silence. Few felt able to talk about what had happened or how they were feeling, even to each other, let alone to their closest family and friends. For some couples, this led to the end of their relationship. Many parents felt completely isolated; they worried that their feelings and reactions and continuing sadness were unacceptable and abnormal.

"We were treated as if something was wrong with us. But we were just grieving." Mum

Some parents didn't give their baby a name, either because nobody suggested it or because they were not told whether their baby was a boy or a girl. Most parents didn't know what happened to their baby's body and didn't feel able to ask. Babies born dead before 28 completed weeks of pregnancy (changed to 24 weeks in 1992) could not be legally registered: parents had no proof that their babies had ever existed. Even when babies were registered, many parents were not given a certificate.

Due to the work of Sands and other organisations, attitudes and practices when a baby died before or around the time of birth gradually began to change.

"We were given some photos of our first daughter but there wasn't one that I felt I wanted to show people. When our second daughter was stillborn I made my husband take a more 'natural' photo of me holding her, and I have this on show in a little silver frame, nestled amongst photos of my other children. But I still wish with all my heart that we had their hand and footprints – even all these years later." Mum

However, many health care staff continued to think that "they knew best". Mothers were regarded as patients and were still expected to accept medical advice without question and to do as they were told.

"We did see and hold our two daughters who were stillborn in 1986 and 1991, and I can't thank the midwives enough for their sensitive and supportive care. However the consultant I was under for our first daughter was extremely insensitive. When I asked my GP to refer me to a different consultant for my next pregnancy, I was told, 'They don't like patients changing consultant so you can't do that'. Why didn't I complain?" Mum

Nowadays, health professionals are far more aware of the impact of the death of a baby. Parents are offered opportunities to see and hold their baby, to name him or her, to collect keepsakes such as hand and foot prints and identity bracelets, and to make their own decisions about funeral arrangements and memorials. Since 1992, babies who are stillborn after 24 completed weeks of pregnancy have been registered, so more parents have a certificate to provide official recognition of their baby's existence. And when a baby is born dead before 24 weeks, the parents are usually offered a certificate by the hospital. Increasingly, people in wider society also recognise that the death of a baby before or around the time of birth is a major bereavement and has life-long consequences.

Although it can be comforting to know that things have generally changed for the better, this doesn't remove the pain of those parents whose care was poor and insensitive. Memories of things that were said, done, or not done can still be very upsetting decades later.

"When I got home after my baby died, I rang my GP's surgery to ask for a home visit. The receptionist said, 'The GP will only visit you if you've got a baby'. The midwife did call round, but she didn't have time to listen and just said, 'I've got mothers with babies to see.'" Mum

Some parents feel guilty that they did not somehow do more for their baby, or make different decisions. If either of you feel like this, it's important to remember that you were doing your best in traumatic circumstances, in a state of shock and terrible grief, with little or no support or information.

Although nothing can change the past, Sands is here to support you if you would like to talk or write about your baby. There are things that you and your family can do now to commemorate a baby who died long ago. In the following pages, we explain how you may be able to trace a baby's grave or record of cremation if you want to try to find out what happened to the baby's body. We also describe some other things that you might like to do.

Stillbirth, birth and death certificates

If your baby was registered as a stillbirth, or a birth and then a death, but you don't have a certificate, you can apply for a certificate now from your national Register Office (see pages 28-29 for contact details).

If you don't have a stillbirth certificate because your baby was born too early to be registered, you could ask an artist or calligrapher to create a commemorative certificate for you. This could include your baby's name, place of birth and birth date, some words from a favourite poem or song, or something you would like to say to or about your baby. Alternatively you can contact Sands to ask for a blank certificate of birth that you can fill in yourself (see page 24 for contact details).

Tracing a baby's grave or record of cremation

It was only in the mid-1980s that the parents of a baby who died began to be consulted about funeral arrangements for their baby. Before then, parents were not usually involved and many were not told what had happened to their baby's body. We know that it can be very important to try to find out, not just for parents, but also for surviving brothers and sisters. However, please bear in mind that it may not be easy and that, sometimes, a search will not be successful.

"Late miscarriages"

Sadly, if your baby was born dead before 1992 and before 28 completed weeks of pregnancy, there will probably be no record of his or her birth, or of burial or cremation. Until 1992, the legal definition of stillbirth was a baby born dead after 28 completed weeks of pregnancy. In 1992, the legal definition was changed to 24 completed weeks. All babies born dead before the legal age of stillbirth are considered in law to be "late miscarriages". Their birth cannot be registered and the law does not require them to be formally buried or cremated, so cemeteries and crematoria have never been required to keep records of these babies.

In recent years, with greater understanding of the significance of the death of a baby at any stage of pregnancy, more babies born before 24 weeks have been formally buried or cremated. Proper records are more likely to have been kept for some of these babies.

Stillborn babies and babies who died after birth

Even though stillborn babies and those who died after birth were registered, it can still be difficult to trace the cemetery or crematorium where the baby was buried or cremated, especially if this happened a long time ago. For example, the hospital where the baby was born may have closed, records may have been lost or destroyed, or, if a funeral director was involved, the firm may no longer be in business.

However, cemeteries and crematoria have always been required by law to keep permanent records of these babies. So if you can identify the cemetery or crematorium, you should be able to find out where the baby's body was buried or the ashes were buried or scattered.

Please note: family members making enquiries on behalf of a parent who is alive will usually need to show a letter of authority from their parent to anyone they contact during their enquiry.

Where to start

You could start by contacting the Bereavement Office of the hospital where your baby was stillborn or died. You will need to tell them:

- ▶ the full name and address of the mother at the time of the baby's birth
- ▶ the date of the baby's birth
- ▶ any other information that you may have, such as the stage the pregnancy had reached.

If the hospital does not have a Bereavement Office, you could try contacting the General Office or the chaplain. If the hospital still has the relevant records for that year, the staff may be able to tell you if your baby was buried or cremated, and possibly the address of the cemetery or crematorium.

Alternatively, the staff may be able to give you the name of the funeral director who made the arrangements. If the funeral director is still in business and still has records from that time, his or her staff should be able to tell you the name of the cemetery or crematorium. You can then contact the cemetery or crematorium staff and ask them to carry out a search of their registers.

However, hospitals don't keep medical records of births indefinitely, and some hospital records may not contain enough detail to be helpful. If the hospital where the baby was born has closed, the records may have been transferred to the nearest large hospital, but sometimes records have been destroyed.

If neither the hospital nor the funeral director has a record of the cemetery or crematorium

You will need to contact local cemeteries and crematoria yourself. Start with those nearest to the hospital where your baby was stillborn or died. If you cannot find any record of your baby at the nearest cemetery or crematorium, the staff there may be able to suggest where else you could ask. You may find the following website useful in finding cemeteries and crematoria in your area: www.iccm-uk.com.

Some cemeteries and crematoria are run by the local council. The council may have a Bereavement Services Department, and the staff there may be able to help or advise you.

By law, anyone can inspect a burial register. However, cremation law only permits the inspection of cremation records at the discretion of the crematorium as there may be data protection issues. (This is because there may be information in the records about people who are still alive.) If you are not able to see the cremation records yourself, the crematorium staff will search on your behalf if you provide the following information:

- ▶ the baby's surname, and
- ▶ the date of the death or stillbirth.

It's helpful to keep a record of your search, including a list of the places you have contacted and the names and contact details of the people you spoke to.

If you find the cemetery or crematorium

You can make an appointment to be shown the exact location of the grave, or the area where the ashes were scattered or buried. Most cemetery and crematoria staff are very helpful and will give you as much information and help as they can. Most cemeteries and crematoria should provide a certified extract from a burial or cremation register.

▶ If the baby was buried

In many places, stillborn babies were buried in a shared grave with other babies. This is still the practice in some cemeteries. Shared graves are not usually marked, though they do have a plot number and can be located on a cemetery plan. Sometimes a baby was buried in a grave with an adult.

Although many parents are pleased to have found the place where their baby is buried, it can also be upsetting, even if the baby has his or her own grave. Sometimes babies were buried in a less attractive part of a cemetery, and some graves may not have been well looked after.

▶ If the baby was cremated

In the past, several babies were sometimes cremated together. This still happens when a hospital arranges funerals for very premature babies. Until recently, ashes were not usually offered to parents following a shared cremation: they were generally scattered or buried, often in a little used area of the crematorium gardens. The crematorium should have a record of where the ashes from a shared cremation were scattered or buried. However, there is unlikely to be a plaque or any formal recognition of the importance of these areas.

If you decide to visit the place where your baby was cremated or buried, you may want to take photographs. However, you may find that there are restrictions on what can be placed on a grave, especially if it's a shared grave. In a crematorium, there may be restrictions on what can be placed in an area where ashes from several babies were scattered or buried. The staff will tell you what is allowed.

You may want to ask if you can have a commemorative plaque, but you probably won't be able to put it on the actual place. Instead, you could arrange for a plaque to be placed elsewhere at the crematorium or cemetery, and to have your baby's name inscribed in the cemetery or crematorium memorial book.

What you could do to commemorate your baby

It's never too late to commemorate your baby. Here are some things that other parents and family members have done. You may have done some of them already.

Visit a memorial garden

There are several Sands memorial gardens around the UK. Our Helpline (020 7436 5881 or helpline@uk-sands.org) can tell you if there is one near you and can give you the contact details.

You could also visit the Sands Garden at the National Memorial Arboretum in Alrewas in Staffordshire. This garden was established in 2000 and is dedicated to the memory of all babies who have died. It is a tranquil place where families can remember their own baby in peace. There is a sculpture in the garden with the inscription "Remembered but un-named", for parents who were not given the opportunity to name their baby. The Arboretum is open every day except Christmas Day.

The paths within the Sands Garden are lined with stones or pebbles on which families have written their baby's name or a short message. If you would like to add your own stone, please use one that is no bigger than 7 centimetres in diameter and write on it or decorate it with indelible markers. Suitable stones and markers are stocked at the shop at the Arboretum.

You might also want to come to the Sands memorial service that is held each June at the National Memorial Arboretum. Information about this service is posted on our website each year in spring (www.uk-sands.org).

Some local cemeteries and crematoria have created memorial areas for babies and children who have died. Even if your baby is buried, or his or her ashes are scattered elsewhere, you may find it helpful to spend time in one of these quiet places.



Come to a Lights of Love service

Sands non-denominational Lights of Love services are held in December every year in several towns in the UK, including London. During the service, parents and families can light a tea light candle in memory of their baby and write a message to hang on a Christmas tree.

The date and venues for each year's Lights of Love services are announced on the Sands website in the autumn. There is also information about how to have a message card placed on the tree if you can't come.

You could also go to a hospital memorial service. Many hospitals organise an annual non-denominational memorial service for babies who have died. You can contact the chaplains at the hospital where your baby died, or at a hospital that is close to where you live, to find out when their service will be held. Some crematoria also hold annual memorial services.

Memorial services can be quite emotional, so you may want to ask a close family member or friend to go with you or to meet you afterwards. You could also let the people who are organising or leading the service know that you might be coming, so that they can look out for you.

Arrange a ceremony to commemorate your baby

You might want to have a ceremony of your own to honour, or perhaps to name, your baby. This doesn't have to be religious or traditional – you could create your own. For example, you could scatter flowers or flower petals on water or at a place with special meaning for you. You might want to ask family members or close friends to do this with you, and you could ask someone to recite a favourite poem or sing a special song.

If you would prefer a religious ceremony, you could ask the responsible person at your own place of worship if they could offer you an opportunity to say a blessing or prayers for your baby. Nowadays it's more widely accepted that the death of a baby needs to be acknowledged in the same way as the death of an older child or an adult.

If you don't belong to a religious organisation, but would like a memorial service with some religious content such as a prayer or blessing, you could approach a local priest, minister or equivalent, or a hospital chaplain. Most hospitals now have representatives of different faiths on their chaplaincy team. Alternatively you could contact the Institute of Civil Funerals (IoCF) or search the internet for an "independent funeral celebrant" who will help you plan a service with as much or as little religious or spiritual content as you want. If you would like a memorial ceremony with no religious content at all, you could also contact the British Humanist Association for advice (see page 27 for contact details).

Other things you might like to do

- ▶ If your baby's stillbirth or birth and death were registered and you don't have a certificate, you can contact the register office in the UK country where the baby was born to ask for one (see pages 28-29 for contact details).
- ▶ Plant a tree or bush in a special place, or perhaps in a large pot so that you can take it with you if you move.
- ▶ Choose a special candle holder and light a candle for your baby on the anniversary of his or her birth, at festivals or at family gatherings.
- ▶ If you didn't name your baby, you can do this now. If you don't know your baby's sex, you could choose a name that works for both boys and girls.
- ▶ Make a piece of cross-stitch or needlework or paint a picture.
- ▶ Write a poem or letter to your baby... just write about what happened.
- ▶ Have a piece of jewellery made, perhaps with your baby's birthstone.
- ▶ Have some glass engraved with your baby's name.
- ▶ Add your baby on to your family tree.
- ▶ Commission a sculptor to create a memorial for your baby.
- ▶ Ask to have your baby's name inscribed in the memorial book at the hospital where he or she was born. Nowadays, most hospitals have a memorial book. Contact the hospital chaplains to ask about this.

- ▶ Raise or donate funds in memory of your baby. Donations to Sands enable us to continue to support bereaved parents, to ensure that they receive high quality sensitive care, and to promote research to find out why babies die. To find out more, please visit the Donate section of our website, email fundraising@uk-sands.org or call 0845 652 0448.

We hope that you have found this booklet helpful. If you would like to talk about any of the things discussed in it, please contact the Sands Helpline on 020 7436 5881. We offer support to anyone affected by the death of a baby, however long ago the baby died.

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 25
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

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

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 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 support in 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

<http://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: staceywills@tamba.org.uk

Other useful addresses

British Humanist Association

<https://humanism.org.uk>

Information about Humanist funeral ceremonies and a list of Humanist funeral celebrants.

Tel: 020 7324 3060 Email: info@humanism.org.uk

Institute of Cemetery and Crematorium Management

www.iccm-uk.com

Develops and promotes best practice in cemeteries and crematoria.

Tel: 020 8989 4661 Email: julie.callender@iccm-uk.com

Institute of Civil Funerals

www.iocf.org.uk

Lists accredited civil funeral celebrants who will accommodate people's wishes, beliefs and values, whether religious or non-religious.

Tel: 01480 861 411 (10am to 2pm, Mon to Fri) Email: info@iocf.org.uk

UK National Register Offices

Obtaining a birth or death certificate

You can order a copy of a birth or death certificate from the General Register Office in the country where the event took place. You can order by post, by telephone or online. Certificates cost £9.25 (2014 prices).

Obtaining a stillbirth certificate

The UK General Register Office's policy states:

"Due to the sensitive nature of stillbirth registrations, the procedure for ordering a certificate of the entry differs from other types of [birth and death] certificates. We will only send out the application form after we have been contacted by phone or in writing by the mother or father (if he is named on the certificate). In cases where the parents are deceased, a brother or sister can apply if they can provide their parents' dates of death."

General Register Office (England and Wales)

www.gro.gov.uk/gro/content/

General Register Office,

PO Box 2,

Southport

PR8 2JD

Tel: 0300 123 1837 Email: certificate.services@gro.gsi.gov.uk

Include "GQ" in the email Subject

The National Records of Scotland

www.gov.uk/national-records-of-scotland *for the online contact form*

New Register House,

3 West Register Street,

Edinburgh

EH1 3YT

Tel: 0131 314 4411

General Register Office for Northern Ireland

www.nidirect.gov.uk/general-register-office-for-northern-ireland

Oxford House,

49 - 55 Chichester Street,

Belfast

BT1 4HL

Tel: 0300 200 7890 (from other UK countries: **028 9151 3101**)

Email: gro.nisra@dfpni.gov.uk

Notes

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

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.

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:

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

Website:

www.uk-sands.org