WHEN A TWIN OR TRIPLET DIES

A booklet for bereaved parents and twins

Supporting Professionals Supporting Families
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With many thanks to Philip and Lucy for their donation towards this booklet in loving memory of Baby Elder, Amy’s Twin.
WHEN A TWIN OR TRIPLET DIES

The death of a child, whatever his or her age, is almost certainly the most devastating event any parent will have to face and many feel very isolated when it occurs.

Losing a twin, triplet or higher multiple baby can be even more lonely because you are less likely to know anyone who has shared this experience and may therefore feel that your own reactions are strange or abnormal. We hope that this booklet will not only give you some useful information about the help that is available to you, including means of contacting other parents in the same situation, but will also help you to understand your feelings of sadness and confusion at this time.

Because some of the medical terms that you may come across can be confusing, we provide a glossary. We also include a list of books and leaflets which parents have found helpful, together with some useful addresses.

BACKGROUND

Many more parents of twins, triplets and higher multiples have to face the tragedy of bereavement than those with singletons, since the mortality rate is much higher from the time of conception.

In the UK, approximately one in 70 maternities results in twins or more. This figure varies in other parts of the world. However, the true incidence of multiple pregnancy is not known because it is not uncommon for one or more of the fetuses to be lost during the first few weeks. This is known as the “Vanishing Twin Syndrome”. Unless an early ultrasound scan has been carried out, many of these pregnancies are not even recognised as twin conceptions.

Later in the pregnancy, one or more of the fetuses may die for a number of reasons. These include some identical twins who suffer from sharing a placenta and blood circulation. In a singleton pregnancy, a baby will be delivered as soon as possible after it has died in the womb. However, with a twin pregnancy the delivery of the dead baby may be delayed for some

* In order to avoid constant repetition, the word “twin” or “twins” throughout this leaflet should also be taken to include triplets and higher order births unless clearly indicated.
weeks in order that the survivor may continue to grow and develop inside its mother for as long as possible.

Twins, and in particular higher order births, are more likely to be born very early and to die because of this premature delivery. All babies who are small at birth are at slightly higher risk of dying suddenly and unexpectedly during the first year (“sudden infant death syndrome” or “cot death”). Later in life, twins are at no greater risk than single children, but if one does die the survivor may be profoundly affected.

The excitement surrounding the arrival of twins means that many parents find they are treated with respect and even admiration by friends and family. If one twin dies, the loss of this special status can cause additional distress, making the birth of only one live baby feel an anticlimax rather than a cause for celebration. Special purchases and preparations made in anticipation of two or more babies, such as a double buggy, larger car, or alterations to the home are all painful reminders of what might have been.

Many parents who lose twin or triplet babies feel that their loss is underestimated, particularly in cases of miscarriage or death in the perinatal period, before other people have had a chance to know the baby. Family, friends and professionals all tend to focus on the surviving child and encourage parents to do the same. They may not even mention the infant that has died. Yet parents often want very much to talk about their dead baby. This is quite natural; indeed, bereaved parents of a singleton would be expected and encouraged to do so.

Understandably, parents usually want to know as much as possible about their baby or babies and to be given a clear explanation of the reason why they died. They may also want to know if the babies were monozygotic (identical) twins. Referred to as their “zygosity”, this can often be determined by examining the placenta or from DNA tests. If necessary DNA tests can be carried out even after the baby has died (for more information contact the MBF).

It is important for parents to ask their consultant and family doctor any questions they may have. Sometimes, medical professionals may not know the answers, either at that time or later on. However, parents should feel confident that all available information is being passed on, and that if they still have unanswered questions, everything possible is being done to search for the answers.

People often imagine that a shared bereavement will draw couples closer together and that they will be able to provide mutual support.

However, this is often not the case. It is not at all unusual for parents to
find that they experience their grief in very different ways or at different times. Such difficulties may mean that they are unable to comfort each other as much as they would like; this can add to the strain (and may even cause resentment) during what is already a very emotionally traumatic time. For those who have been through many years of infertility and now fear that they may never conceive again, the pain and stress may be especially great.

Loss during pregnancy
The loss of a baby before 24 weeks of gestation is referred to as a miscarriage or spontaneous abortion. In a multiple pregnancy, one or all of the babies may be miscarried. Many parents who have experienced a miscarriage may have received perhaps well meaning but nevertheless, unwelcome and unhelpful comments such as “it’s for the best” or “it’s nature’s way”. Such reaction suggests that a miscarriage is a minor event. However, many couples will feel their loss profoundly, especially if this was a long awaited pregnancy or one that followed infertility treatment.

In a multiple pregnancy it is not unusual for one of the fetuses to die very early in the pregnancy, and for that fetus to be reabsorbed into the placenta. This is known as the “Vanishing Twin Syndrome”. At other times, one fetus may miscarry and the pregnancy continues normally with one baby.

When one baby or more survives
Parents who have lost one or more of their multiple birth family and still have a surviving baby face a complex and difficult time. They have a constant reminder of their loss in the survivor, particularly if they were monozygotic twins. Other people may fail to realise or to recognise the extent of their bereavement, and, because parents are left with a surviving baby or babies, the loss is often underestimated. Hurtful, though well-intended, remarks may be made such as, “it would have been hard to cope with three babies” or “you are lucky, at least you still have one baby”. These comments are made usually by people who are uncomfortable when talking about death, and particularly the death of a baby.

Many parents find it almost impossible to grieve for a baby who has died whilst at the same time caring for and rejoicing in the survivor. Conflicting emotions and mood swings ranging from joy to despair can often seem inappropriately timed and the resulting feelings of guilt can further increase distress. The problem is made worse if everyone is encouraging parents to focus their whole attention on the living child. One of the unique difficulties
for those with a surviving twin or triplet is that, because it makes it easier for people not to have to talk about the dead baby, the survivor tends to receive all the attention and comments. In some cases, the infant who has died is not even mentioned. This can be very hurtful.

Sometimes parents know from the time of birth (or even before) that one of their babies is going to die during the newborn period. This means that they may have only a short time to give their care and love to the dying baby and to say goodbye. They will need support and encouragement to make this time special for them and their baby. They will often want to talk about their baby to the hospital staff, not least to help them feel that the dead baby is real, special and distinct from the surviving child. There should be no feelings of guilt about not devoting time to the healthy baby during this period - there will be many years ahead in which to do that.

**Triplets, quads and more**
The loss of one or more babies in a higher multiple set can be particularly difficult. They may miscarry before they are viable; they may die one by one soon after birth or over many months. If a couple is left with two or more healthy babies it is unlikely that they will receive much sympathy. Outsiders may well feel that they have enough children. Yet to the parents each child is equally precious. The attention of the media often adds to their distress.

**Sudden infant death**
No parent can ever prepare adequately for the loss of a baby and to lose a baby in sudden and unexpected circumstances, such as a cot death, is inevitably a traumatic experience for all the family.

Much is now written about sudden infant death and parents can find a range of information on how best to try to ensure the safety of their babies. Following the unexpected death of one twin, parents will naturally be anxious for the other. Indeed it does appear that the surviving child is at somewhat greater danger of also dying during the next month (the most critical period being the first few days). After that time, the risk to the remaining twin is no greater than for all babies of that age group.

Some doctors recommend that the surviving baby be admitted to hospital for a few days’ close supervision and monitoring. Parents should not feel that, if this happens, professionals think they are incapable of looking after their own child. This is certainly not the case.

Once the baby returns home, an electronic ‘apnoea monitor’ may
be provided, which will sound an alarm if the baby stops breathing. This is often reassuring but it can be stressful if, as not infrequently happens, the monitor gives ‘false alarms’. Parents, in discussion with their doctor, will decide what is best for their particular circumstances. The organisation CONI (Care of the Next Infant) provides helpful information on the care of subsequent children and of surviving twins following a cot death.

PRACTICAL TASKS

Some hospitals have a bereavement midwife/nurse who can talk through all the options available and help with guidance about the practical aspects and the paperwork.

Registering the death
The death of babies born after 24 weeks of pregnancy and of older children must be registered within 42 days at the local Registrar of Births, Deaths and Marriages (usually situated close to the Town Hall or Council Offices). The hospital chaplain, social worker or a named midwife will be able to help you with this, or you may prefer to approach your own minister of religion.

It can be very distressing to have to register simultaneously the live birth of one twin and the death of another, so it may be helpful to be accompanied to the Registrar by a friend or relative.

Birth and death announcements
If parents of twins lose one of their babies it can be difficult to know how best to inform relatives, friends and working colleagues. Choices include:

- A birth announcement in the newspaper which also mentions the baby’s death, e.g. “On 1 February, twin girls (Jane and Sarah). Very sadly, Jane died soon afterwards” or “Very sadly, Jane was stillborn.”

- A similar announcement sent on a card to individual people.

- A death announcement in the newspaper which might contain mention of the surviving twin, e.g. “On 1 February Jane, stillborn twin sister of Sarah”. In this case, a birth announcement would probably be made too.

Details of any funeral or memorial service can be included in each case.

Funerals and memorial ceremonies

Babies
Parents will need to decide whether their baby should be cremated or buried and whether they want an individual or shared grave. Some may want to have a single, named grave for their baby (which can also be shared if both twins die) or they can have a memorial stone if the babies are cremated.
It is important that the hospital staff know as soon as possible that you wish to make your own arrangements for your baby’s service. However, this does not mean that you need to feel rushed into organising everything very quickly. Many parents need to spend time with their baby, perhaps on more than one occasion, before they are ready to say goodbye.

Some families find it helpful and comforting to spend time planning the funeral or memorial service. An organisation “Not Out Of Mind” publishes a booklet with material to help parents to design their own service.

Other people may prefer to leave all the arrangements to the hospital and they may hold a memorial service later on. Some have done so many years later; others include a prayer for the baby at the baptism service of the surviving twin. Hospitals arrange for communal burials so, unless you request otherwise, your baby will be buried with others. Some parents may find this comforting.

The law does not require a funeral for babies who are born before 24 weeks (this is still legally defined as a miscarriage). However, parents may wish to arrange their own service and there are many clergy or ministers of religion who will be prepared to conduct it.

**Older children**

After the death of an older child, the parents will have to decide how closely the surviving twin should be involved in the funeral arrangements. This will include such issues as seeing their twin’s body. For many children it can be reassuring to see how peaceful their brother or sister looks after they have died. They may find it an important part of saying goodbye. Others are comforted by decorating the coffin and helping to plan the ceremony.

It is a personal decision whether or not the child should attend the funeral. Even a young child may express his/her own wishes about this and they should be taken into account where possible.

**Naming the baby**

Most parents feel that it is important to name the baby that has died. This enables them to clearly distinguish him or her from their other baby and it is also easier for friends and relations to be able to refer to the dead child by name. Later on, the surviving twin may also find it helpful. Hospital chaplains will be able to baptise a dying baby if parents request it. Even babies who are miscarried or stillborn can be “baptised by intent”. Many clergy will be happy to perform this ceremony (sometimes years afterwards) and parents often derive great comfort from it, as well as treasuring the certificate of baptism.
COPING WITH BEREAVEMENT

No couple or individual will grieve for their baby in exactly the same way. Inevitably, therefore, each person has to find their own way to cope with their loss. We can only describe some examples of support and strategy that others in a similar situation have found useful. We hope that you may find one or two of them helpful too.

Someone to talk to
Some people will find the support they need within their own circle of friends and family. Others will welcome contact with:

- A bereavement counsellor, either in the hospital or in the community.
- Another bereaved parent of twins (or triplets). Your hospital, health visitor or local Twins Club should be able to give you an introduction.

Otherwise:

- The Twins and Multiple Births Association Bereavement Support Group (Tamba BSG) has a countrywide network, as well as running meetings and publishing a regular newsletter.
- The Multiple Births Foundation can provide information, support and counselling for bereaved parents and for the twins themselves.

Something to read
There are many books and leaflets written for bereaved parents in general as well as a few specifically concerned with twins. A selection is listed at the end of this booklet.

Creating memories
For most parents it is important, later on if not at the time, to have as many substantial reminders of their baby as possible. Sometimes, particularly with stillborn babies, there will not have been time to gather memories of time spent with the baby, so special mementoes may need to be created.

Photographs, drawings and paintings
At whatever age the baby dies, a photograph (even if only of the ultrasound scan) can be precious to parents. Such a reminder may be painful during the early days, but the hospital can always be asked to keep it safely in case it should be wanted later on.

Parents often want photographs of themselves holding their babies and perhaps to include other members of the family in the picture, particularly brothers, sisters and grandparents. This is also helpful to any children born in the future.

Many parents want a picture of the twins together, and often deeply regret that one was never taken, if 7
one baby was stillborn or died soon after birth. In these cases, an artist can often do an attractive sketch of the babies together - taken from two separate photographs.

Some parents find that the photographs of their babies, although very precious to them, are not pictures they feel like sharing with friends or putting on display. A sketch or painting may be more appropriate for this. Photographs can always be taken of these pictures to give to grandparents, brothers and sisters.

Even when only one twin dies, it is important for the families and the surviving twin to have photos taken of both together. This may be the only tangible reminder that they were twins.

Mementoes
These can be especially important for those who have no photographs of their babies. Anything belonging to the baby can be very precious in providing a tangible reminder of his or her existence, such as:

- foot and hand prints
- a lock of hair
- a hospital wrist band
- the baby’s blanket or hat
- cards and letters from friends and family

Other memorials
Different forms of memorial can give long-lasting comfort to parents and also remind other people of your baby. Ones that the MBF has been told about include:

- a tree, a flower or a shrub in a special place
- a special vase for flowers
- lighting a candle at special times such as anniversaries
- a framed tapestry with the baby’s name and date of birth and death
- an ornament or picture bought in memory
- a garden bench under a favourite tree
- a bird bath or small statue

Most hospitals have a book of remembrance for babies in which parents can have an inscription entered. The MBF and Tamba BSG each have their own book specifically for multiple births. Entries can be made at any time. Contact the two organisations for details.

Writing and painting
These are other helpful ways of expressing and sometimes coming to terms with your feelings (including those of anger and resentment). There seems to be no time limit to this and some parents have found writing about their experience enormously helpful, even many years later. Other creative writing or art can produce very personal and special reminders of their baby.
Birthdays and anniversaries
These are often especially difficult times for parents. If their surviving twin is celebrating a birthday on the same day that their other child was stillborn, the parents are bound to have very mixed emotions. In some cases they may even find, to their distress, that they resent the survivor. It may be helpful to set aside a time (perhaps early in the morning) specifically to remember the baby that has died. Many parents find that this enables them to enjoy the rest of the day and to celebrate with the surviving child.

Possible ideas for this special time may include:

- a visit to the grave or memorial.
- listening to a favourite piece of music
- going for a long walk

Other parents may want to remember their child on the birthday with, say, a candle, a special card or an arrangement of flowers.

If the surviving twin is celebrating their birthday with a party, it can help to have a close friend or family member with you, who can take over the party for a while if you find you need a little time away from the festivities.

THE SURVIVING TWIN

Even when the death has taken place at the time of birth, parents will of course be concerned for their surviving child and what effects the loss of their twin may have on them. We are often asked questions such as: “Will they know they are a twin?” “Should we tell them? If so, when?” “Will they be lonely?”

There has been little research into the emotional effects of being a surviving twin or triplet. However, our experience with many bereaved families supports the findings of a study of 200 adult surviving twins by Joan Woodward, a psychotherapist and herself a surviving twin. She found that many felt their loss profoundly and that they found it most difficult if the parents were unable to talk to them about their twin or made them feel that they had, in some way, been responsible for their death.

Generally, it is easier if the survivor knows from the start that he or she is a twin. Nowadays, parents are more likely to be encouraged to speak freely about their dead baby and to prepare themselves for any questions that their child may ask. Many children are proud of their twinship and will want to talk about their twin. Conversations tend to be made easier if the baby has been given a name and/or if
there are photographs (even if only an ultrasound scan) or other mementoes for the child to see. By talking openly and honestly, children are much less likely to have problems in coping with the bereavement.

The older child
Most of this leaflet is concerned with the death of a baby because many more babies die than older children. However, some older children do die be it from an accident, chronic illness or acute infection and the effects on the survivor may be devastating. Much of what has been written in this leaflet is relevant to bereaved parents of older twins too. But such parents will have the added strain of caring for a child who has lost her closest companion and friend, someone who has been with her throughout her life. With identical twins, in particular, the constant reminder of the dead child in the survivor may add to the family’s pain.

People who are not twins rarely recognise how intimate and constant the twin relationship is. The loss of this partner can be profound. Where possible, the healthy twin should be as closely involved with the brother’s or sister’s illness and death as their level of understanding allows.

Older children may be helped by talking to adults who have shared their experience. Introductions can be arranged through the Multiple Births Foundation or through the Lone Twin Network (LTN).

The LTN is a nationwide network to which any adult bereaved twin can belong. It enables twins to be in touch with others who have shared a similar experience. Its members include those who have lost their twin from early in the pregnancy to old age.

SELECTIVE FETICIDE AND MULTIFETAL PREGNANCY REDUCTION

Occasionally parents who are expecting twins or higher multiple births have to face the agonising choice of whether to sacrifice one or more of their babies. This can arise in two situations:

- one fetus has a serious abnormality
- there are so many babies that there is a high risk of all the babies being miscarried or dying because they are born too early.

In these cases, couples will be helped to consider whether or not to have a selective feticide (for an abnormality) or a fetal reduction of their higher order pregnancy. Parents will, of course, be given information and counselling before they make such a difficult decision. The MBF has published leaflets on both these dilemmas and they may be useful in helping people to understand the procedures and their implications.
WHERE TO GET HELP

There are a number of organisations that offer bereavement support. The addresses of some of them appear at the end of this booklet. However, parents who have lost one or more of a set of twins, triplets, quads or more may feel that they need help from people who have special experience in this area.

The Multiple Births Foundation (MBF)

The MBF was founded in 1988 to provide professional support for families with twins, triplets or more. Its primary aim is to improve the care of these families by raising awareness of how to meet their special and particular needs. This is achieved mainly through the education programme for health care and other professionals but it also offers some services to the families themselves.

Bereavement Services
Bereavement support is an important part of the work of the MBF. Many people find the easiest way to find help is by telephone – at least in the first instance. MBF staff can usually provide immediate information and ongoing support. If specialist help is indicated, arrangements can be made for bereaved parents, children or adult twins to speak to the MBF Counsellor.

If it is known that one baby has already died or is likely to do so, soon after birth, an appointment can be arranged for parents to talk to one of the MBF staff before the babies are born. The MBF provides an advisory service for professionals such as midwives, doctors, health visitors teachers and social workers, by telephone, letter or email. One of the MBF “Guidelines for Professionals, Multiple Births and their Impact on Families” is concerned with bereavement.

The Twins and Multiple Births Association (Tamba)

Tamba, formed in 1978, is the UK parent support organisation and umbrella for many twins clubs. The Twins and Multiple Births Association Bereavement Support Group (Tamba BSG) is one of its important special groups.

The BSG provides a network of contacts for bereaved parents as well as a regular newsletter. The group also runs meetings for bereaved parents.

The Lone Twin Network (LTN)

The LTN was set up in 1989 and provides contacts through a national register for adults who have lost their twin at any time from a miscarriage to late adult life. The Network holds regional meetings as well as an annual national meeting.
FURTHER READING

For parents – Twin Loss


For parents - General

Heartbeats; A Collection of Poems. CLIMB Inc. PO Box 1064, Palmer, AK 99645. 1995.


For adult twins


For children


For professionals


RESOURCES

Being Yourself, Deal, Kent CT14 7NN. Books/Games for adults and children to help with their bereavement.

Not out of Mind: Prayer When a Baby Dies. Resource material to assist those who wish to create services of prayer for babies who died before or at birth. WREN publications, PO Box 396, St Albans. Herts AL3 6NE. Tel 01727 761719.

Artists
John Mackrell
2 Edderston Farm Cottages
Peebles
Borders
Scotland EH45 9JE
Tel: 01721 724393

Joy Cuff
158 Church Road
Teddington
Middlesex TW11 8QL
Tel: 020 8977 7407
ADDRESSES

The Multiple Births Foundation (MBF)
Level 4 Hammersmith House
Queen Charlotte’s Hospital
Du Cane Road
London W12 OHS

Tel: 020 8383 3519
Fax: 020 8383 3041
E-mail: mbf@hhnt.nhs.uk
www.multiplebirths.org.uk

Tamba (The Twins & Multiple Births Association)
2 The Willows
Gardner Road
Guildford
Surrey GU1 4PG

Tel: 0870 770 3305
Fax: 0870 770 3303
E-mail: enquiries@tamba.org.uk
www.tamba.org.uk

ARC (Antenatal Results and Choices)
73 Charlotte Street
London W1T 4PN

Tel: 020 7631 0280
Helpline: 0207 631 0285
E-mail: info@arc-uk.org
www.arc-uk.org

Care of the Next Infant (CONI)
Details obtained via FSID

Child Bereavement Trust
Aston House
West Wycombe
High Wycombe
Bucks HP14 3AG

Tel: 01494 446648
Helpline: 0845 357 1000
E:
enquiries@childbereavement.org.uk
www.childbereavement.org.uk

Child Death Helpline
Great Ormond Street Hospital
Great Ormond Street
London WC1N 3JH

Tel: 020 7813 8551
Fax: 020 7813 8516
Helpline: 0800 282986
www.childdeathhelpline.org.uk

Compassionate Friends
53 North Street
Bristol BS3 1EN

Tel: 08451 203785
Fax: 08451 203786
Helpline: 08451 232304
Email: info@tcf.org.uk
www.tcf.org.uk
CRUSE
Cruse House
126 Sheen Road
Richmond
Surrey TWG 1UR

Tel: 020 8939 9530
Fax: 020 8940 7638
Helpline: 0870 167 1677
Young Person’s Helpline: 0808 808 1677
E: info@crusebereavementcare.org.uk
www.crusebereavementcare.org.uk

The Foundation for the Study of Infant Deaths (FSIDS)
11-19 Artillery Row
London SW1P 1RT

Tel: 0870 787 0885
Fax: 0870 787 0725
Helpline: 0870 787 0554
E-mail: fsid@sids.org.uk
www.sids.org.uk/fsid

The Miscarriage Association
c/o Clayton Hospital
Northgate
Wakefield
West Yorkshire WF1 3JS

Tel: 01924 200795
Fax: 01924 298834
Helpline: 01924 200799
E: info@miscarriageassociation.org.uk
www.miscarriageassociation.org.uk

SANDS (Stillbirth & Neonatal Deaths)
28 Portland Place
London W1B 1LY

Tel: 020 7436 7940
Fax: 020 7436 3715
Helpline: 020 7436 5881
E-mail: support@uk-sands.org
www.uk-sands.org

Lone Twin Network (LTN)
PO Box 5653
Birmingham B29 7JY
GLOSSARY OF TERMS

Abortion
The termination of a pregnancy either spontaneously (see miscarriage) or by medical intervention.

Embryo reduction
See multi fetal pregnancy reduction.

Fetofetal Transfusion Syndrome
See twin-twin transfusion syndrome.

Twin - twin transfusion syndrome
Condition in which blood from one identical twin fetus transfuses into the other via blood vessels in the placenta.

Fetus
Unborn baby from eight weeks of pregnancy until birth.

Fetus papyraceous
A fetus that dies in the second three months of pregnancy and becomes compressed and parchment-like.

Higher order birth/higher multiple
Triplets or more.

Infant death
Death in the first year of life.

Miscarriage
A spontaneous abortion.

Multi fetal pregnancy reduction
The reduction in the number of viable fetuses/embryos in a multiple (usually higher multiple) pregnancy by medical intervention.

Multiple Pregnancy
A pregnancy with more than one fetus.

Neonatal death
A death in the first four weeks.

Perinatal death
A stillbirth or death during the first week.

Selective Feticide
The medical termination of the life of an abnormal twin fetus in a continuing pregnancy.

Stillbirth
A baby born with no sign of life.

“Supertwins”
Higher order/multiple birth.

Vanishing twin syndrome
The death of one twin fetus early in the pregnancy and its reabsorption.
Further Information

For more information about the Multiple Births Foundation, call us on 020 8383 3519 and request an information pack.

Alternatively, you can log on to our website, at: www.multiplebirths.org.uk to find out more.

The Multiple Births Foundation is a charity and relies for its income on grants, donations and fundraising activities.

The Multiple Births Foundation
Hammersmith House, Level 4
Queen Charlotte's & Chelsea Hospital
Du Cane Road
London W12 0HS

Tel: 020 8383 3519
Fax: 020 8383 3041
Email: mbf@hhnt.nhs.uk
Website: www.multiplebirths.org.uk

Registered Charity no: 1094546
Limited Company no: 4426289

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