

# TAMBA BEREAVEMENT SUPPORT GROUP BOOKLET

FOR PARENTS WHO HAVE  
LOST ONE OR MORE BABIES  
FROM A MULTIPLE BIRTH

BY DR. ERIKA FRASER

# TAMBA BEREAVEMENT SUPPORT GROUP

The bereavement support group (BSG) was established in 1982 in response to requests from parents who had lost a twin. All BSG befrienders are volunteers who have suffered a loss from a multiple birth either during pregnancy, at birth or at any stage after birth.

None of the befrienders are 'professionals', they offer a befriending rather than a counselling service, although BSG does have access to professional support if required. Contact with another parent who has gone through a similar experience can be a source of great help in learning to live with the loss and in overcoming the enormous sense of isolation parents can feel, no matter how sympathetic and supportive family and friends are.

Bereaved parents come to us in a variety of ways and we appreciate that people need different levels of support. Some people just want to be supported by e-mail. Others might want a one off phone call, whilst some need ongoing support through the early months, subsequent pregnancies, or for several years after. Likewise, some people contact us straight away in the first few weeks, whilst others take longer to make the first contact.

In order to help as many families as possible we are always looking for more volunteers to become befrienders. If you think you or your partner could be a befriender, please contact Carol on [carolclay@tamba.org.uk](mailto:carolclay@tamba.org.uk) or call 01483 304442.

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 specific circumstances. Tamba does not accept any liability, including liability for any error or omission.

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# FOREWORD

The Tamba Bereavement Support (BSG) group exists to support all parents and carers who have lost from a multiple birth whether it is during or after pregnancy. We are so sorry for your loss and hope that by reading this booklet you will find some comfort to help you.

*Carol Clay*

*Tamba's Twinline and Supports Group Coordinator*

# INTRODUCTION

The experience of being a bereaved parent of multiples is a devastating one, full of conflicting emotions. Parents often feel overwhelmed by the sheer intensity of their feelings. Sadly, the loss of one or more baby is not unusual, with two babies lost for every 100 multiple births. Please do not feel isolated in your grief. You are not alone – the bereavement support group at Tamba is run by parents for parents. We know how special it is to have fallen pregnant with multiples and the complicated emotions you will be feeling right now.

Although bereavement can be a lonely process, other people can help support and care for you. If you are finding it difficult to discuss what you are going through with your friends and family, please contact us via our website ([www.tamba.org.uk/bsg](http://www.tamba.org.uk/bsg)) or phone Tamba's Twinline (0800 138 0509) or the Tamba office (01483 304442). There is also a list of other organisations at the back of this booklet, which may be of help to you at this time.

We have produced this booklet to share our experiences and personal stories with you and to help you through the challenging times ahead. People experience grief differently, so some of this booklet may not reflect your own situation or your feelings. Please remember that however you react and whatever thoughts you have, there is no right or wrong. Follow your instincts – you know what is best for you and your family.

This booklet includes sections for fathers, surviving twins, siblings, grandparents, and other family members or friends who wish to help. It also provides ideas for remembering, coping with anniversaries and creating memories, as well as sections on caring for a surviving baby, returning to work and subsequent pregnancies. Please note that while this booklet uses the term 'twin' for ease of reading, we intend for the information to apply to triplets and higher order multiples as well.

We hope that this booklet provides some comfort. Please remember that we are here to listen and help when you're ready to talk.

# IF YOU ARE STILL PREGNANT

## ...BUT ONE BABY HAS DIED

When one baby dies during pregnancy, doctors often advise mothers to 'go longer' to give the surviving twin the best possible start in life. Parents in this situation often feel extremely shocked and distressed about the loss of their baby, but also the special experience of being a parent of twins. They may also feel grief on behalf of their surviving baby and the loss of their future relationship with their twin. It is not unusual to feel uncomfortable or ashamed if you didn't realise one of your babies had passed away, but few parents ever suspect anything is wrong until the terrible shock during the ultrasound examination, when no heartbeat can be found.

Parents often worry that the grief and anxiety will harm their surviving baby. They may try to bottle up their sorrow, which isn't helped by not being able to say goodbye to their baby or have a funeral for several days or weeks. It can be a very difficult time, stranded between death and starting the process of bereavement.

The knowledge that you are still carrying both life and death can also be disconcerting, but there is no evidence to suggest that the surviving twin will be emotionally or physically impacted by continuing to share the space.

Not knowing 'why' your baby has died can also be extremely painful for

parents, both in terms of coming to terms with what happened, but also the fear that the unexpected may happen again. Without an explanation for one baby's sudden and inexplicable death, it is natural to feel vulnerable and scared about the well-being of your surviving baby. Although your pregnancy is at a higher risk and your doctors will want to conduct frequent medical examinations to check everything is ok, the research suggests that outcomes are usually good, especially for fraternal (dizygotic/non-identical) twins. You may find this extra level of care reassuring.

## ...BUT KNOW THAT ONE OR BOTH BABIES WILL DIE SOON

If you are reading this in the knowledge that one or both of your babies has a condition that means they will die later in the pregnancy or shortly after the birth, we are very sorry. A natural reaction is to put up mental barriers to prepare yourself for the imminent loss. But you may also be torn between protecting yourself and enjoying your time with your baby cradled inside you, talking to, singing to, and caressing it.

Living with the uncertainty of whether your baby or babies will be stillborn or whether they may live for a few days, weeks or months is extremely distressing. Perhaps you don't know whether you will have a chance to say hello and goodbye, to see them look back into your eyes and to hold your babies together. This time in limbo is extremely stressful, but please know that you are not alone and there is support available, either through Tamba's BSG or one of the organisations at the back of this book.

## MY STORY OF LOSING ONE TWIN DURING PREGNANCY, BUT 'GOING LONGER' FOR THE SURVIVING TWIN CLARE NORMAN

I realised I was pregnant in May 2003 and looked forward a little anxiously to the scan. When the day arrived, the sonographer was very kind. Almost immediately she told me she could see a heartbeat, which relaxed me, but then followed up with questions as to whether I had been feeling very sick and whether there were twins in the family. There was silence as the implications of what she was saying sank in and then she said 'Congratulations – you are expecting twins!'

Despite feeling extremely shocked at this news I felt ecstatic – how wonderful and very special. However our happiness was short-lived as the

sonographer started to say she had concerns that one of the babies was very small. She felt the babies were sharing the same placenta and there was a danger of a condition called twin to twin transfusion syndrome. We did not understand what she meant and sat in a daze waiting to see the consultant. After what seemed like an age, a consultant talked to us but was unwilling or unable to give us any further information. Eventually he suggested an urgent appointment at our regional neonatal department. We went home and my husband spent time looking up information on the internet and tried to prepare me for the worst-case scenario – that neither of our babies would survive.

After a sleepless night we went for the appointment and another scan. The new consultant explained that the twins were non-identical and therefore the twin-to-twin condition was not an issue. He did feel however that we would encounter a syndrome

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called 'vanishing twin' where in the early stages of pregnancy one twin 'disappears'. We found this extremely upsetting and spent some time trying to come to terms with the news. We clung to the hope that the consultant might be wrong, whilst also preparing ourselves to see only one baby at the next scan. We had also been told that if the twins did survive the smaller twin was likely to have a chromosomal or genetic disorder. We could have tests to determine this, but there was a risk to both babies with any procedure.

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Our minds were in turmoil as we did not want to put either baby at risk.

Amazingly, at the next scan both heartbeats were present and the babies were growing – we were elated that the smaller baby was still alive and went away feeling more hopeful.

So the weeks passed with scans every two weeks. At various points, it appeared both babies were growing, although one was always at a slower rate. At other points, concerns were raised about the smaller baby, in particular the possibility of a hole in the heart. An urgent appointment at Great Ormond Street was very distressing as we sat and watched sick children being wheeled around. However, no defect was found and

again we clung to the hope that all was well. Our lives were driven by the next hospital appointment and everything else faded into insignificance. The one thing that kept me going over those worrying months was the knowledge that one baby appeared healthy and thriving.

At about 32 weeks we were again told that our smaller baby appeared to be growing very little and the possibility of a heart problem was again mooted. Another gruelling journey to Great Ormond Street

brought the devastating news that our little baby did indeed have a hole in the heart. We were told that this problem could be rectified, but that the slow growth was a possible indicator of additional problems, in which case surgery might not be viable. I was devastated and sat crying in the canteen. We were toying with delivering early if it would give our baby a chance of survival... but how would that affect our other twin?

Our consultant was very clear and told us that by delivering now it was highly likely we would lose our little baby and the best option was to continue and talk to the paediatric surgeon about surgery after the twins were born. We endured another long

week on a rollercoaster of emotions.

The day of the next scan arrived. The consultant swept the scanner quickly over my stomach and I just knew. He paused and pointed out the larger twin's heartbeat – a pause – “I'm sorry your other twin has died.”

I felt numb, shocked, devastated. We were shown to a quiet room where we sat and cried in private. I felt anger and sadness – why us?

We found out the sexes of our babies at that point – we were told we had lost a little boy and that our little girl was alive and well. I was strongly advised to continue with the pregnancy to ensure the best possible outcome for the surviving twin. I felt drained and exhausted. How could I endure another six weeks knowing my baby had died? The following weeks and days were a blur, with Christmas an ordeal to get through. I shut off completely in order to cope. It was too painful to think about, let alone talk about.

A Caesarean was booked for New Year's Eve and at last the day arrived. I just wanted the pregnancy to be over at this point and all the warnings about possible early labour had proved unnecessary. Our babies were born and the first lifted up to us – a beautiful squealing baby BOY! We were again shocked and elated. After so many certainties, we had achieved an element of surprise – a beautiful boy we thought we would never see. The birth of our little girl was a complete contrast. We later asked to see her and for me it was not so much upsetting as a reality check. Looking at my daughter

was confirmation for me that I had indeed lost my little baby. We had a blessing for our daughter we named Isobel with our son Harry with us, and a few days later held a simple service and burial for her.

The next few months were an overwhelming mix of emotions – happiness at having my son Harry and overwhelming sadness at not having Isobel. Small difficulties took on huge proportions for me – any little thing would upset me. We found out that our daughter had Edwards Syndrome, a chromosomal disorder few children survive. My overriding worries were that Harry would be affected in some way by having lost his sister and also be affected by me being so upset. I tried desperately not to be emotional in front of him. I felt robbed of the all-consuming happiness new mothers should feel and some days were really bleak.

Three years on and I have begun to adjust to life as it is. I have realised as Harry has grown that my fears about him have not so far been borne out, and indeed he is a beautiful happy little boy. I have come to recognise the triggers that will upset me and act as reminders of what I have lost. These will always be there as Harry gets older and reaches milestones in his life.

At one time I believed I could never go through another pregnancy and the fact that last year I had another beautiful little boy, Ben, is evidence that time does heal. Although I deeply miss having Isobel here with us, I know she will always be part of our family and will never be forgotten.

## WHEN ONE OR BOTH BABIES DIE:

### WHAT MAY HELP DURING PREGNANCY?

#### You may want to ...

- Name the babies.
- Keep talking – your partner, family and friends can be of enormous support.
- Please contact Tamba's Bereavement Support Group if you would like to speak to someone who has been through a similar experience.
- Keep a journal, scrapbook, baby book or memory box to gather mementos.
- Write your birth plan - you may wish to ask for a quiet environment for the birth, with as few staff as possible. After the birth, you might prefer a private room and to put up a 'No Visitors' sign.
- Think about whether you would like to remember the birth. Many parents whose baby/babies died are grateful that they do remember the birth or regret being too drugged to remember. If you would prefer not to have general anaesthesia or drugs that fog your mind, mention this in your birth plan.
- If your baby has been dead for a while before the birth or has a serious abnormality, talk to your doctor and midwives about what your baby might look like. Parents rarely regret seeing their babies in this condition, although they may feel sad later that they cannot share the photo with others for fear of unsettling them. The hospital staff can help support you in saying goodbye, including wrapping the baby sensitively.
- Plan in advance which relatives and friends you would like to have meet the twin(s) who have died. This helps to make the baby a real person to

other loved ones. Even young children appreciate knowing that they got to meet their baby brother or sister and say goodbye.

- Start thinking about burial/cremation arrangements and what kind of ceremony you would like.

#### If you have a surviving baby, you may also like to:

- Talk to, sing to and stroke the surviving twin.
- Talk with your doctor if you're worried about a surviving baby's health.
- If people ask what presents to get your surviving baby, consider also asking for something to remember the sick baby or baby who has died, such as charitable donations.
- You are entitled to grieve for your loss - don't allow your doctor or midwives to ignore the baby who has died, or your emotions, or tell you "just focus on the healthy baby."
- If you would like to keep visual memories of your babies, ask for a picture (of both/all babies) whenever you have an ultrasound. You may also want to take photos of you pregnant too.
- If your surviving baby is likely to require neonatal care, look around the Neonatal Intensive Care Unit (NICU), meet the staff and try to ask any questions, so that it will not be totally unfamiliar if one or both/all babies are there.

*Adapted from information provided by: (1) the Center for Loss in Multiple Birth (CLIMB); and (2) Multiple Births: Bereavement Support, Canada.*

## DIFFERENT KIND OF LOSS

Losing a baby is always a tragedy, no matter how many babies you lose or at what stage it happens. Parents who have lost both their babies often feel extremely

empty and talk about a 'deafening silence'. All the excitement of being pregnant with more than one baby seems like a lifetime away and parents can feel extremely alone, with nothing left but disappointment, anger, and sadness. The loss is more than just the loss of the babies - it is a complex process of loss which is explained more in the box on

## UNDERSTANDING YOUR LOSS

### SOME OF THE COMPLEX EMOTIONS THAT PARENTS HAVE AFTER LOSING ONE OR BOTH OF THEIR BABIES

#### Coping with the loss of your babies

- the loss of your dreams for the future – the life your family would have had together.
- having no visual image of what your babies would have looked like.

#### Loss of a unique parenting experience

- feeling cheated of the special experience of having a multiple pregnancy.
- feeling heartbroken at the sight of a double buggy and jealous of other pregnant women, especially those expecting twins.
- not being acknowledged as a parent of twins by others.
- sadness for others' loss, especially surviving twins, partners and siblings.

#### A general sense of loss about life itself

- feeling that a part of you has died.
- feeling abandoned by God or that life has no meaning anymore.
- loss of trust in life and your body, which you may feel has betrayed you.
- feeling frightened by not knowing what you believe in anymore.

#### Dealing with your feelings

- the pain of not knowing why and feeling tortured by the 'what if' question – could you have done anything

#### differently?

- the mistaken idea that you didn't love your babies enough to keep them alive.
- regret or guilt about worries you may have had about being a parent to twins.
- feeling out of control – worrying that this amount of grief cannot be normal.
- feeling ashamed or that you have let others down, even though this feeling is completely unjustified.

#### Dealing with your loss around others

- coping with other people's insensitive comments or thoughtless attitudes, some with the best of intentions.
- dealing with your feelings over others' pregnancies, especially those expecting twins or due around the time your babies would have been born.

#### A continuing sense of loss about what the future holds

- not knowing how long your feelings will last or if you'll ever be the same again.
- the possible loss of your last chance of having a baby because of age, an inability to pay or be eligible for further fertility treatment.
- the anxiety felt for subsequent pregnancies.

'Understanding your loss'.

If you have a surviving twin, you may feel that your heart is breaking for their loss and your loss. You may feel guilty for having these feelings, when you think that some people lose both children or are never able to have children. But please remember that your grief is valid – your surviving child is a blessing, but they are no consolation for what you have lost. The hole where your absent baby should be cannot be filled and you will never stop thinking about them, but you will eventually find peace.

Tamba's BSG supports parents experiencing all sorts of loss and this section covers the most common types of bereavement. Please remember that you are not alone and we are here to help.

## LOSS DURING PREGNANCY AND BIRTH

Miscarriage and stillbirth can be a terrible shock and parents often feel overwhelmed by feelings of disappointment, sadness, confusion, anger, jealousy, loss of control, guilt and inadequacy. It is important to remember that it is not your fault – please do not blame yourself or feel guilty.

Parents are often plagued by the 'Why?' question – 'Why did this happen to us?' - both at a medical and a philosophical level. At most hospitals, you will be asked for your permission to conduct a post-mortem if your baby or babies died after 14 weeks. Although it is not always possible to provide a full explanation for why babies die during

pregnancy or birth, finding an answer can be helpful. It can also provide useful medical information for subsequent pregnancies, both for yourself and for other women's pregnancies in the future.

Losing one or both babies during pregnancy is not typical of other bereavements in that sometimes your sense of loss is not understood or validated by others, which can leave you feeling confused and to question your feelings of grief. The bond between expectant mother and unborn babies is real and your grief is a valid reaction.

If one or both babies die after 14 weeks, you may be able to see them if you wish. If your babies have grown enough and the loss happened in hospital, you may be asked if you would like to hold them and dress them. Although it is upsetting saying goodbye to your babies, many parents say it is a special moment they will always treasure. If you are unsure whether you want to do this, your midwife or doctor can describe the babies, take a photograph first and talk with you and support you until you are ready to make a decision about this difficult moment.

When babies die during pregnancy or birth, mothers often continue to experience physical symptoms in the first few days and weeks, relating to the aftermath of birth. Your body's physical reactions can feel like a betrayal – even if all your babies have died, your breasts may still produce milk. Losing your baby weight is dispiriting at the best of times, but when you have nothing to show for it, it can be an emotionally painful reminder. Some women also find their arms ache from the instinctive urge to hold their baby in the first few weeks and months. It is also normal to dream that your babies are still alive or to think you hear them crying.

## MY STORY OF MISCARRYING BOTH TWINS: JAY HARPER

I was so happy to be pregnant with twins. To then be told at 10 weeks that only one would survive was heartbreaking, but I still held out hope of at least having one baby. But by the next time I was scanned at 14 weeks, both babies had died, which was absolutely devastating. Apparently they had a very rare thing called TRAP Sequence, which only happens in 1 in 64,000 twin pregnancies. The smaller twin didn't have a proper functioning heart so the larger twin was pumping blood to the other baby and around it as well. So it was putting a lot of strain on its poor little heart. There was realistically no chance of either surviving, but the doctor who saw me

was a horrible experience as well. I saw both babies as I was giving birth to them and I couldn't stop crying, it was horrible. I just kept thinking "I should be doing this for real and taking them home!"

Afterwards I lost a lot of blood. It was a nightmare and I was lucky to have my wonderful husband with me the whole time. I then had to try and push the placenta out but it wasn't having any of it. Apparently it was sitting at the top of my cervix but didn't want to come out, which was why I was passing big clots of blood. So at about 10 o'clock, they put me on a drip for two hours to try and force it out, but still no joy. They then decided

I would have to go & have a D&C to get it out. This didn't happen until 2am, by which time I was absolutely exhausted. What should have been an easy procedure, ended up being yet another bit of agony for me.

I took a lot longer to come around after the procedure than I should have because

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of having asthma. My husband was frantic with worry in case anything had happened to me, because he would have lost the twins and me. To me, it didn't seem a long time, but I was gone for two hours! I lost a lot of

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blood, so when I got back I was very weak and couldn't stand up unaided at all. They said I would be staying in overnight anyway by this stage, so to rest up and they would monitor my blood pressure throughout the night.

By the next day I was still unable to walk unaided, so they decided they would have to give me a blood transfusion, but only one bag. When I eventually left the hospital at 5pm I was still really unsteady on my feet. I needed constant care for about two weeks and iron tablets to bring my blood levels back up to speed.

We had a cremation for the twins on 4th January 2007 and my sisters came along to support us. We scattered the ashes in our favourite place in Wales, where we can visit them anytime we want to.

Their due date of 11th June 2007 passed and I kept thinking, "What if they were born? What would they be doing?" It was a difficult time, but I fell pregnant in April with one baby, which took the sting off things a little. I can't say being pregnant again makes you forget, but it scared me that this pregnancy would end the same way. I will never forget my twins as long as I live; they have a special space in my heart.

I had several scans: the first two were at a specialist hospital in Birmingham at 8 and 10 weeks. These were to make sure all was well and that it was a single pregnancy. They then discharged me and I had a 12-week scan, which was also normal and the baby was growing well. I then had a triple test at 16 weeks, which came back as high risk for Down's Syndrome.

I really did think the world was against me when I got that call. The next stage was to decide if I wanted an amniocentesis to confirm for sure if the baby did have Down's Syndrome or not. We decided we did want to go ahead just to be sure one way or another.

After the amniocentesis we were told I had to rest for three days due to the risk of miscarriage. Even if the baby was fine, I could still lose it. That was the longest week of our lives, waiting for those results to come back. Luckily the test came back negative, which was great and it also told us we were having a little girl!

I then went on to have my 20 weeks scan which was fine. Throughout my pregnancy, my mind was still a little apprehensive. Until I get to hold my baby in my arms, I couldn't fully relax.

I already had an 11 year old daughter from a previous marriage and she was devastated about what happened with the twins. So to be told she was going to have a little sister made her dream come true and she could not wait for her to be here.

My little baby girl was born on 25th January 2008 - 12 days late - but a wonderful belated birthday present for me (my birthday is on 18th January)! But she was worth the wait to say the least. We called her Gia (which means Soul) and we treasure her as our little miracle baby. I can safely say this baby is loved and spoiled by everyone because we have waited so long and gone through so much to get here. We thought we were cursed and would never have a baby of our own but then along came our little beautiful girl.

## MY STORY OF THE STILLBIRTH OF ONE TWIN AND HAVING A SUBSEQUENT TWIN PREGNANCY

I was informed in January 2003 that I was expecting twins. This was a shock (I knew nothing about twins, apart from there are none in our family).

My antenatal care was unremarkable, and the only comment I really remember, was one midwife telling me I was a model of a perfect twin pregnancy.

I had discussed with my obstetrician about various deliveries on or around 37 weeks and in the meantime I would just carry on "as normal".

In July 2003 I went for a regular midwife appointment at 35 weeks where she seemed to have a very

this point I was blissfully unaware of any problems. Hence I went for lunch with my partner and we then went back for the scan.

The next few hours are very painful to recall. The sonographer couldn't find a second heartbeat and I was sent up to see my obstetrician who confirmed that one of my twins had died. It didn't sink in. My partner and I rang our mothers, and family. We were told that it was important that I went into surgery immediately.

My sons were delivered that afternoon. Alexander was stillborn and William was initially stable. I only

saw William for a few minutes before he was taken to ICU. By this time the families had arrived and we were all taken to a private room where the catholic priest baptised Alexander. William then became very unwell and for the next three weeks it was touch and go as

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minor problem finding a second heartbeat. She did find it after a while (we now know she was just listening to the same heartbeat twice). I had a scan booked later for that day anyway, so she asked me to check the heartbeat with the sonographer. At

to whether he would make it. I have never felt so sad, or frightened in my life, but luckily I had my family to help me through this. William eventually grew stronger and is now a noisy bouncy 6 year old.

In March 2007 I found out I was



expecting twins again. Of course the pregnancy was very closely monitored and a very traumatic time. At 14 weeks it was seen that one of the twins was much smaller than the other. Twin to Twin Transfusion Syndrome (TTTS)

inconclusive. To this day we will never know why he died. William knows all about his twin brother, and is very happy to have two other brothers. I suffered severe postnatal depression after both my pregnancies.

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was discussed, as was what we would do about it. At 24 weeks, although one twin was much smaller than the other, TTTS was discounted. My obstetrician was able to get me just past 28 weeks, when it was decided very suddenly that the twins would be delivered as one had stopped growing. Matthew (although very small) was quite well within a week of being born. Daniel (even smaller) had various problems and went home on oxygen for 6 months 10 weeks after being born. They are now healthy fun two year olds.

The post mortem on Alexander was

I don't know whether this would have happened in other circumstances. My partner and I still have "sad times" especially on the first twin's birthday and also just at random times. My partner finds it very hard to talk about Alexander. William is very keen to talk about his brother, so I have just had to get on with it and deal with it. I now am a befriender for Tamba and I find this helps me as I am the kind of person who talks about these things. I still find it hard to cope with, and am still sometimes very upset, but life has had to go on, and I am lucky to have my other three children.

“ I STILL FIND IT HARD TO COPE WITH, AND AM STILL SOMETIMES VERY UPSET, BUT LIFE HAS HAD TO GO ON, AND I AM LUCKY TO HAVE MY OTHER THREE CHILDREN. ”

## AFTER YOUR BABY OR BABIES DIE:

### SOME IDEAS

- Hold your baby/babies and say goodbye, if you would like. If you don't want to see your baby immediately, you could ask the hospital to take photos and keep the photos on record until you're ready to view them.
- Name your babies.
- Create a memory box, including items such as: ultrasound pictures, wrist tags, locks of hair, cot cards, birth notes, photos of your babies, photos of yourself pregnant (even if you didn't look or know you were pregnant), both congratulation and condolence cards/flowers/gifts, favourite baby clothes or blanket, birth and death certificates.
- Have a photo/picture reproduced from ultrasound scans. Some parents like to take photos after the birth, including both/all babies together, parents holding the babies, and a photo of all the family together, including the baby who died.
- Some hospitals have memorial books or can arrange memorial plaques.
- Ask for your babies to be tested to see if they are identical or not.
- Arrange a funeral/baptism/memorial service.
- Decide if you want a post-mortem examination to be conducted.
- Consider sending a birth announcement, which remembers the loss of your other baby.
- Talk to your GP, a professional counsellor or join a support group.
- And finally ... do what you think is right for you.

## SPECIAL SITUATIONS

### TWIN-TO-TWIN TRANSFUSION SYNDROME

TTTS is a rare, but potentially fatal, complication in identical twins, whereby one baby (the recipient) gets too much blood and the other (the donor) gets too little. TTTS can sadly cause the death of one or both twins, either due to prematurity, death in-utero or as a result of birth defects. Although parents who have been bereaved due to TTTS have the small comfort of having a medical explanation, they are often shocked and upset that health professionals were not able to save their babies' lives. Some parents feel they were not given enough information or made aware of the warning signs. Others may have been closely involved in the choices of treatment and feel tortured by the thought that they might have chosen the wrong option.

### FETAL REDUCTION

Parents who lose a baby through a fetal reduction procedure are likely to have mixed emotions. On the one hand, they are aware that by not continuing with a higher multiple pregnancy, they have increased their chances of having at least one healthy baby (if not two). But on the other hand, parents can also feel guilty about the decision and what might have been. They may feel they were pressured into a decision and didn't have enough time to think about it. Parents can also torture themselves with the big 'What if?' question – What if we had not gone ahead with the procedure? Could the babies have been born healthy?

The random nature of fetal reduction

can also be upsetting – why should one baby die, while the others live? This is a troubling issue, especially for surviving multiples, who may feel that their multiple died in order to save them. The question of whether to tell your children is problematic, but if you think there is even the remotest chance they may find out from somebody else, it is best to be completely honest. You may wish to let your children know from an early age that they had a brother or sister who died when they were in mummy's tummy. However, you don't need to explain exactly what happened or the nature of the procedure while your children are still young.

### ABNORMALITY REDUCTION

You may also have had to make the difficult decision to go through with a selective feticide procedure if one of your babies had a serious abnormality. As well as the conflicting feelings of losing one baby while the other survives, parents often find it difficult to come to terms with the aftermath of the procedure and carrying one dead baby next to the live one for several weeks.

## LOSS IN INFANCY

If your babies were born alive, but died in the first few months of life, it is likely that you will have spent some time in the Neonatal Intensive Care Unit (NICU), also known as the Special Care Baby Unit (SCBU). Parents often feel extremely torn.

If one twin is doing well, you may have

felt divided, practically and emotionally, between caring for your healthy twin and devoting all your time, love and attention to your poorly twin in NICU.

If both your twins were in NICU, you may feel remorse that you did not get the opportunity to hold your babies as much as you would have liked while they were alive or struggled to know which baby needed your care most.

You may also have regrets that you were pressurised into making decisions you weren't comfortable with, you did not have enough information to make the necessary choices or you did not have the time to think them through. It is important that you felt involved in the decisions and arrangements for the care of your babies, both when they were alive and in the time after they passed away.

Many parents find the hospital chaplain to be a good source of support during this difficult time. The chaplaincy team is usually multi-denominational and even if it has no non-Christian staff it should be able to put you in touch with ministers of other faiths. You can talk to a member of the team whether or not you are religious or Christian.

When babies die in hospital before they have been able to come home, parents often feel confused – was it all just a dream? Although some parents never want to return to the place their babies died, others do not want to leave the safe confines of the hospital, the only home their babies ever knew. It can also be hard leaving behind sympathetic doctors and nurses who knew your twins and who you have got used to sharing your feelings with. You may like to return to talk to the people who knew your babies, or spend time in the hospital gardens.

When a baby or child dies after a life-threatening illness, you may have

experienced a prolonged period of fear and uncertainty. The stress of knowing that you are powerless in the face of your children's pain and distress can be overwhelming. Parents have been on an emotional roller-coaster of fear, but also hope that surgery or medication may have brought an incredible recovery.

It can also be hard to balance the needs of your sick child with your other children and you may have felt torn about where to devote your energy and time. Even though you and your family may have lived under the shadow of death for some time, death still comes as a shock. Parents can feel worn down by the stress of battling their baby's illness and the dashed hopes, leaving them few resources left to cope with their grief. Others may expect you to be relieved that your child is no longer in pain, but it is normal to wish they were still with you, no matter what their suffering was or however selfish this may seem.

Returning to normality after the unsettling period of caring for an ill child, with nothing but grief and memories left, can feel lonely and unreal. Some parents find it helpful to busy themselves fundraising for the hospital, medical research or a charity that supports families affected by their baby's illness. You may also like to set up a trust in their memory.

### COT DEATH

The sudden and unexpected death of a baby is a terrible shock. Parents often blame themselves or perhaps medical professionals who saw their baby. No matter how many times you are reassured that it was not your fault, the guilt (however unjustified) can take a long time to go away. The Foundation for the Study of Infant Deaths (FSID) has a helpful

booklet 'When a baby dies suddenly and unexpectedly'. You may also like to call their Helpline (0808 802 6868) to talk to a trained adviser (10am-6pm) or trained bereaved parent befriender (6pm-11pm) about your loss.

You are also likely to feel frightened for your surviving twin that they too are vulnerable to cot death. Your GP or hospital may suggest that the surviving twin goes into hospital for a brief period of observation, as there is a slightly increased risk (especially during the first few days). Although it is extremely rare for more than one twin to die of cot death, doctors sometimes recommend monitoring the surviving twin under hospital supervision. Please do not think this means that health professionals think you are unable to look after your babies or even that you were in any way responsible for the cot death – it is a standard procedure to ensure the safety of your surviving child during the short critical time period following their twin's sudden death. You may also be provided with an electronic 'apnoea monitor' to use at home. The monitor sounds an alarm if your baby stops breathing, which can be reassuring, apart from the very stressful times when it occasionally gives a false alarm.

FSID run a programme called Care of the Next Infant (CONI), which supports parents when they have another baby, but also provides extra reassurance to parents of twins. Parents can monitor their baby's progress using symptom diaries, weighing scales, movement monitors, thermometers, weight charts and regular visits from health visitors. It is available through hospitals and community health centres. To find out if there is a local CONI scheme in your area, please call FSID's helpline.

## MY STORY OF COT DEATH JENNY WIGHTWICK

My multiple pregnancy was 'discovered' on my first scan at 16 weeks. Geoff and I were hoping for a healthy sibling for our son, Thomas, who was 16 months at the time. Twins were 'diagnosed' initially. My mother is a twin and Geoff has twins in his family so it was always a possibility, but was still a bit of a shock. However, a week later, a further scan revealed triplets. The pregnancy went ok, and as expected. I had periods of total exhaustion as the babies zapped all my nourishment, but they seemed to flourish.

I went into spontaneous labour at 35 weeks gestation and gave birth naturally to triplet girls: Lucy, Alice and Eleanor on 21st April 1989. They weighed in at 4lb 14oz, 4lb 10oz and 4lb 12oz respectively and all seemed well. Eleanor and Alice were breech deliveries, but relatively uneventful due to their small size and all three were taken to SCBU to be checked over and where pronounced fit and well. I remember them being so very noisy! Alice and Eleanor were identical, so much so that we had to look at their name bands to tell them apart. Lucy was different. All three were just beautiful.

I recovered well, and was allowed home after a couple of days, without the babies (they were having difficulty feeding so this needed to be established before coming home)

but Tom and I visited them every day and helped with feeding and bathing. All went well and I relished my time at home to recover my strength in preparation for bringing the latest additions to our family home.

Two weeks later the big day arrived. Fear and trepidation ruled our thoughts - how were we going to manage? I had already engaged a mother's help to be with me during the day. She was an absolute godsend and there is no way that I would have coped and remained sane without her.

We had a phone call the night before the big event, I remember that Geoff and I had gone to bed. It was about 11pm and we were reading. Geoff answered the phone to be told by the hospital that Eleanor had contracted meningitis, but not to worry. The disease had been detected early and treatment commenced straight away and that her chances were very good. We were stunned and just did not know what to think, but had been advised that the girls would not be coming home the next day. All three were being treated with the same medication and were in the best place for the time being. I accepted this and continued with my daily visits with Tom. Eleanor appeared to recover well.

Two weeks later Lucy, Eleanor and Alice came home. I remember three car seats on the kitchen floor with one sleeping baby in each and Tom

rushing outside to play in his sandpit, seemingly oblivious. Geoff and I just stood there looking, not knowing what to think.

Then the fun and games began! My life became one long feeding, changing, bathing, burping session. Tracy, my adored and valued helper, would look after the babies whilst I escaped with Tom for a walk or visit to the parent and toddler group a couple of times a week. Exhaustion did not

with the children.

My sister's wedding was truly magical. Tom was a pageboy and for once the total focus was on him and he loved it and relished it. Geoff and I felt good too and we all went to bed that night exhausted but happy.

The next morning I got up early to feed the babies who had begun to stir. I was armed with three bottles ready for action. I remember thinking that Eleanor looked cold, she was still and

her covers had come off. I went to replace the covers but flinched. My hand seemed to touch marble and I just stood there. She was dead. I shouted for Geoff, who came running. Our worst fears had been realised. It was July 25th, Geoff's and my wedding anniversary.

“ALICE AND ELEANOR WERE IDENTICAL, SO MUCH SO THAT WE HAD TO LOOK AT THEIR NAME BANDS TO TELL THEM APART. LUCY WAS DIFFERENT. ALL THREE WERE JUST BEAUTIFUL.”

begin to describe how I felt, but I was also very proud and a little euphoric and soldiered on. All four children thrived and the babies gained weight – Geoff and I lost it but that did not seem to matter!

When the babies were 3 months old, my sister got married and we all ventured to Norwich for the big event. My mother suggested staying for a few days with her so that Geoff and I could have a bit of space and lots of help

Eleanor had suffered a cot death (also known as 'sudden infant death syndrome' or SIDS). How are you supposed to feel? We still had two babies and Tom. My initial reaction was 'I will be able to cope now' for which I felt such guilt and shame for years after. It was a perfectly normal reaction, I have since been told.

Eleanor was buried in Norwich. I recollect the day as being like a film in slow motion, flashes of people

holding back tears, a tiny white box, kind words, false jollity from me – I had to stay strong. I remained in denial for about 3 months but then fell apart and ended up taking anti-depressants for the next 6 months.

I had never felt so alone in my life. Geoff and I dealt with the loss of Eleanor in very different ways which put a huge strain on our marriage. I needed to talk and make sense and cry, but he remained seemingly passive and unemotional (of course he was suffering too, he just kept it all within). It was an extraordinarily difficult time for us.

Now I have reached a stage where I can think of the events and am able to put them in a place where I can reflect. I have learnt to live with my experiences and our loss.

My gorgeous girls are now 21 years old, both at university and I am the proudest mother in the world. Tom also is a joy and coming up for 23 years of age. Time is a great healer - that much is true. We have been challenged as a family more than most, but our experiences have cemented my marriage to Geoff (now in our 29th year!). Our tragedy changed us

“ NOW I HAVE REACHED A STAGE WHERE I CAN THINK OF THE EVENTS AND AM ABLE TO PUT THEM IN A PLACE WHERE I CAN REFLECT. I HAVE LEARNT TO LIVE WITH MY EXPERIENCES AND OUR LOSS. ”

As human beings, we do not want to feel different or stand out from the crowd and I was no exception to this. I was desperate to be like every other mother of three children, but I was not. I had two of triplets, a little boy and a cot death to deal with. Times were very hard and on reflection, I craved the friendship of another human being with the same experiences as I, but found no one. So I kept busy, instead of talking about how I felt. This led to periods of depression, trying to make sense of what happened.

forever, but not in a bad way. I visit Eleanor's grave in Norwich whenever I am there. My mother tends it most of the time and I believe this has helped her come to terms with the loss of her granddaughter.

On reflection, having the support of other parents in a similar situation to me would have helped so much, but hindsight is a wonderful thing. I see now that I should have talked more and opened up, but it is never too late.

## THE FIRST FEW WEEKS: ARRANGING THE FUNERAL/ MEMORIAL

For many parents, funerals and memorials are their chance to say goodbye in whatever way they think most fitting. You may want to celebrate their life, however short it was, or to talk about your feelings of loss. By choosing poems, a reading or prayer or by playing a favourite piece of music, you can acknowledge how important they were to you. The book 'Not Out Of Mind' by Althea Hayton provides some suggestions for funerals, memorials or service of prayers for families bereaved by miscarriage,

stillbirth, neonatal death or the death of a baby.

For some families, religious or cultural beliefs will require you to organise a funeral very quickly, sometimes within the first 24 hours. If this is the case for you, please mention it to the hospital and they can help arrange the necessary paperwork urgently.

While many people choose a traditional funeral, you may prefer a less formal or non-religious arrangement. It is important you choose what is right for you and your family.

### ARRANGE FUNERALS AND CEREMONIES

Once you have registered the death, you will need to choose a funeral director and start thinking about the type of funeral arrangements you want. When a baby dies in hospital, the midwife or nurse can help explain what your options are,

## BURIAL OR CREMATION:

Some of the decisions for you to consider as a family, with advice from your funeral director, include:

### Burial:

- Where can the burial take place? Options include: churchyard, municipal cemetery, natural burial grounds, private land.
- What personal belongings do we want to include inside the coffin?
- Do we have ownership of the grave? And if so, for how long?
- Can both twins be buried in the same coffin?

### Cremation:

- Will there be any ashes left to

scatter? (Not usually the case for young babies).

- Is all the official documentation ready for the cremation?
- Has the crematorium allocated enough chapel time for the service? Can we book a double time-slot if we prefer?
- Can we include any personal items in the coffin, and if so, are there any restrictions?
- Can we order a plaque or plant a tree, flowering shrub or rose bush within the crematorium's garden of remembrance?
- Can we write our child's name in the Book of Remembrance?

what the hospital offers, and make the arrangements for you. If parents accept the hospital's offer, they should be able to attend, bring flowers, and participate in different ways (depending partly on whether it is an individual funeral or one for several babies).

If you prefer to arrange the funeral yourself, it can be helpful to break down the arrangements into a list of small jobs to order your thoughts, as well as helping you see where others could help. Parents on low incomes who want to organise their own funeral may be able to get a Funeral Expenses Grant.

Some people like to recognise the specialness of the relationship between twins in their choices, for example how they dress their children, their choice of poems or readings. Some suggestions of poems are provided on Tamba BSG's website [www.tamba.org.uk/bsg](http://www.tamba.org.uk/bsg). If there is a surviving child, you might like to place a cuddly toy in the coffin or piece of jewellery on their body and keep an

identical one for their twin.

If your babies died during pregnancy, it might be possible to arrange a memorial and burial service. Some hospitals or clinics allow you to arrange a burial within the grounds. It is also possible to arrange a cremation at the hospital and some local crematoriums offer this service, although they have no legal obligation to do so. Please note that you may not have any ashes remaining from the cremation of foetal tissue from a very young baby.

You can also have a burial at home, but you will need to talk to your local authority about this. If you decide to bury your babies at home, some parents place their babies in soft material inside a box and bury it in the garden. Some parents prefer to use a waterproof box, in case they wish to take it with them if they move at a later date. Others plant the bodies by a young tree in their garden and the growth of the tree gives comfort to them in the months and years to come. Even

“ WHILE MANY PEOPLE CHOOSE A TRADITIONAL FUNERAL, YOU MAY PREFER A LESS FORMAL OR NON-RELIGIOUS ARRANGEMENT. IT IS IMPORTANT YOU CHOOSE WHAT IS RIGHT FOR YOU AND YOUR FAMILY. ”

if you don't have anything left of your babies to bury, you can still remember them by planting a tree or flowering shrub in your own garden, a memorial garden or a park. Some parents prefer to use a tub, so they can take it with them if they move.

### PLAN A MEMORIAL CEREMONY

You may also wish to mark your loss with a memorial ceremony, however small or informal. It may simply be a case of lighting a candle and saying a few words with your family. Other parents like to make a symbolic gesture, such as releasing balloons, butterflies or birds. It is your family's opportunity to say your last goodbye, so it is important you do whatever feels appropriate to you, your customs, culture and beliefs.

### BIRTH AND DEATH ANNOUNCEMENTS

Finding the right words to express your loss in formal announcements can be a heartbreaking task, but also a healing activity that helps your loved ones share in your joy and sorrow. Many bereaved parents say it is important that people know how proud they are to be a mother to these babies. The Center for Loss in Multiple Birth (CLIMB) has several examples on its website: <http://www.climb-support.org/>

### ARRANGE WORDING ON HEADSTONES

You may also want to acknowledge the fact they were twins on the headstone. If one twin survives, some parents like to acknowledge the surviving twin on the headstone, for example by writing 'Twin to ...'. If you have other children, they can also be included on the headstone, for example, 'Beloved younger sister to Thomas and twin to Mark'.

If both babies died, parents often recognise their special relationship in the headstone wording, such as 'Together Forever'. One family arranged for a headstone in the shape of Noah's ark with the inscription 'They came two by two'.

### SAYING GOODBYE

Funerals and memorials provide parents with the opportunity to say goodbye, but there are also other ways you can remember your child. For example, some parents like to write a letter to their babies or child. You can tell them how much you loved them, what they meant to you, and all the things you wish you could have told them. It does not have to be a final goodbye letter, if this is too painful. Writing down your feelings either in a daily diary or as poetry is another therapeutic way to express your grief.

## CHILDREN, FUNERALS AND MEMORIALS

### SOME ISSUES TO CONSIDER

- Children value the option of attending the funeral of a family member and, while difficult, it is a good opportunity to say goodbye and accept the finality of the death. Children often have regrets later if they are not allowed to participate, and this is particularly true for surviving twins. However, it is your family and you know best whether their attendance is appropriate and whether it will cause extra stress for you or the children themselves.
- If you are worrying about how you will react, you might want to consider

getting a family member or friend to take on the role of supporting your children so you can grieve freely.

- You may also want to talk through what will happen beforehand, so that your children are prepared – what will happen, how long it will last, and who will be there.
- Even if the children do not attend the funeral, it is never too late to say goodbye. Later in this booklet, we provide some ideas for marking the anniversary or remembering a lost brother or sister.

# IMPACT ON OTHER FAMILY MEMBERS

## PARTNERS

People grieve in a variety of ways. Some people are more introspective and grieve privately, whereas others prefer to express their emotions and mourn openly. How you grieve depends upon your personality and cultural expectations. There are also differences between the way men and women react to loss.

It is easy for women to misinterpret their partner's reaction as not caring,

and for men to think that women are too emotional or unable to put things behind them. It is quite normal not to know why your partner is reacting a certain way, and indeed they may not be able to identify with your grief either. Differences in relating to each other's behaviour can lead to you starting to drift away from your partner or resent each other. It is important to remember that there is no right or wrong way to grieve and that how a person acts is not necessarily a true indicator of how they are feeling. By recognising these differences, you can avoid misunderstanding each other, just at the very time when you need your partner most.

## HOW WOMEN GRIEVE

Women tend to be more expressive of their emotions and may need to cry and be sad. Bereaved mothers are often more 'loss-oriented' and may need more time to talk about their suffering. Many women grieve more openly and like to share their feelings with other people. Dwelling on memories and lost hopes is an important part of the female grieving process - women may want to remember their child, not be distracted. When a death happens in early pregnancy, women often feel the loss more intensely. Although fathers may have hopes and dreams for their unborn children, the bonding process often does not start until they feel the babies kicking, see the ultrasound pictures, or even when they first hold their babies in their arms after the birth.

## HOW MEN GRIEVE

Men are traditionally expected to have a 'stiff upper lip' and to show less emotion. Bereaved fathers therefore tend to find more solitary ways of grieving and to control any public shows of emotion. Men are less likely to be offered, or to seek, outside support. They are usually more 'problem-oriented' and may concentrate their energies on seeking information about the cause of death. Men also tend to be 'restorative' and move past the emotional stage of loss quicker, looking for a way forward to feel better and to function normally again. Men are more likely to feel nervous about what will happen if they 'lose control' and they may try to keep busy to forget their pain. This may include immersing themselves in work, sport, or a hobby.

## THE LOSS OF OUR TWIN BOYS – A FATHER'S GRIEF MATT FROUD

My wife and I underwent IVF in September 2008. Our first cycle of IVF went very well and we ended up with five good quality embryos that stood a good chance of surviving. As a result of my wife's ovaries being rather swollen due to the treatment, we were advised to only put back one embryo. We followed the advice and a few weeks later we were ecstatic to find out it had been successful. We knew that it was early days and aware it could still be a rocky road ahead, but we were at least on that road at last.

We had our first scan a few weeks later and were absolutely stunned to find out that the embryo had split into two and we were pregnant with MCDA identical twins. At the time, statistics showed that there was about a 2.3% chance of this happening and we were told we could be in for a very complex pregnancy, which would include many additional risks. We were both so excited, but also very worried and didn't really take all the information in at this point...

As the pregnancy moved on, we were sent to Queen Charlotte's and Chelsea Hospital for fortnightly scans. At around 17 weeks, we had a scan and came out to the waiting room as normal while we waited for our notes to be written up. A few minutes later the sonographer called us back in for a chat. He told us that one of our boys

had a reduced amount of fluid around him and was around 25% smaller than his brother. We were told not to worry, but he wanted to keep a close eye on things and wanted to see us for weekly scans from now onwards. As you can imagine we went home very worried, but we did feel we were in the best hands and continued to go for our regular weekly scans.

As the weeks went on, the fluid reduced and the size difference increased. Both of our boys' dopplers were always good and their hearts and other organs seemed to be functioning well. At week 29, the size difference reached around 57% and it looked as though the smaller baby's growth had started to tail off. The doctor advised that we had a planned c-section the following Monday at 30 weeks and 3 days, as he felt the babies now had more chance outside of the womb with the help of Neonatal Intensive Care than they did inside. The following day I came out in chicken pox! If we didn't already have enough to worry about, we now didn't know whether I would be allowed into the hospital and the c-section was only 10 days away. I sent my wife into the hospital urgently to get a preventative injection to try and prevent her and the boys from catching it. Luckily she did not catch it and I made a quick recovery and although looking rather unsightly I was allowed into theatre on the day.

We went in for the c-section on Monday 27th April 2009. The c-section went extremely well and both our boys were born at 12:29 & 12:31 respectively. Oliver weighed 1400grams and his little brother Joseph just a tiny 635grams, we couldn't get over the size! We were still very worried, but we knew we were in a great hospital. All the staff had been amazing and if anyone could help then we were in the best place. In the first few days, both boys seemed to be doing very well, then on day

We were both in complete shock, but we also knew we needed to stay strong for his brother Oliver. Oliver was doing really well, his feeds were being gradually increased and he managed to move out of intensive care and into the special care baby unit that night, so we didn't have to go back into the high dependency unit after Joseph's death. We lived about an hour and a quarter from the hospital, but we visited Oliver every day.

Alongside this, we also had to

“ ALL THE STAFF HAD BEEN AMAZING AND IF ANYONE COULD HELP THEN WE WERE IN THE BEST PLACE. ”

6 Joseph suddenly developed NEC (necrotising enterocolitis – a disease involving infection and inflammation that causes destruction of the bowel, or part of the bowel).

It was a very severe case of NEC and his bowel eventually perforated. The doctors arranged for a Neonatal Transport team to take him to Chelsea and Westminster hospital for surgery, but he was never stable enough to move, let alone be operated on. We were absolutely devastated, but we had to accept there was nothing anyone could do for our little man. Joseph had lots of cuddles from us and his grandparents before the doctor removed his life support and he eventually died in my arms at 15:05 on Monday 4th May at just over 1 week old.

get on with registering the births, Joseph's death and all the funeral arrangements. A few days later I developed a throat infection and had to stay away from the hospital for a few days, but my wife visited every day. My wife then developed Mastitis in her breasts and was in agony for many days so felt unable to visit for a few days. I eventually got over my throat infection and managed to visit Oliver on Tuesday 19th May, the day before Joseph's funeral. We had a wonderful day with him, the nurses were all saying how well he was doing, he was the top baby in the nursery!

The day of Joseph's funeral came. It was extremely upsetting, we gave him the best send off we could. We finally arrived home that evening and both burst into tears. An hour later we

received a call from the hospital to say Oliver has been sick twice in the last few hours and wasn't very well. They told us not to worry too much, they had stopped his feeds for the time being and were keeping a very close eye on him. They suggested we got a good night's sleep and came in in the morning. We were so shocked as we began to re-live Joseph's death.

We decided to go straight in and we arrived at about 10.30pm that evening. He looked like a different baby. He was back in an incubator with all the monitors back on him, and his tummy was distended just like Joseph's had been before he died. We feared the worst, but tried so hard to keep positive. We were told that they thought he had developed NEC. Our hearts nearly stopped, we couldn't believe it could happen to us again. He was doing so well just 12 hours earlier, even the nurses were so shocked to see him change so suddenly. We both went through the same emotions, trying to support each other along the way.

We were told it didn't look as severe as Joseph, but they were pretty sure it was NEC all the same. They took regular blood gasses and x-rays of his tummy. The last x-ray showed his bowel had perforated, but they couldn't tell how bad it was from the x-ray. Unlike Joseph though, he was stable enough to be transferred to Chelsea and Westminster hospital for surgery and the surgeon was happy to try to operate and see if he could save our little boy. It seemed to take forever for the Neonatal Transfer team to arrive. They had come all

the way from Margate as the London ambulances were all busy. Eventually they arrived and made our Oliver stable ready for his journey. We were told to make our way to the Chelsea and Westminster, so we were there ready to sign consent forms and speak to the surgeon prior to surgery. Oliver overtook us in the ambulance as we were stuck in all the Chelsea Flower Show traffic, but we eventually met up with him at the other end. The surgeon spoke to us and explained all the risks, but he thought he was in reasonable shape for his condition and would stand a reasonable chance of survival. They then took him down to theatre to prepare him for the operation. We said a quick goodbye to our little man and then we went to have some dinner as we knew it would be at least two hours before we would be able to see him again.

We returned from dinner and went back into the parent's room and waited for the news, it felt forever. Eventually we noticed the surgeon arrive back. He was talking to someone outside our room, but I could tell by the look on his face the news was not going to be good. He entered the room and sat down with one of the consultants. He told us that he was very sorry, but when they opened up his tummy, his entire small intestine had been destroyed by the disease. Removing it was not an option; he could not survive on his large intestine alone. We just couldn't believe what we were hearing! He said they had stitched his tummy back up so we could see him for as long as we wanted before they eventually

removed his life support. Myself, my wife and both his grandparents spent time cuddling our little man in his last hours. We eventually decided it was time to let him go and we asked the doctor to remove his breathing tube. He was still on morphine and very sedated, so could feel no pain. I continued to cuddle him until he finally slipped away to be with his brother.

We just cannot understand why life has been so cruel to us. To a degree, we had sort of come to terms with losing Joseph as he was so small and we believe he had given up his life to help his brother survive and thrive. But now Oliver has died we just don't know what to do or where to turn. It is as if our future and all our hopes and dreams had all died along with our boys. We like to think that Oliver just missed his twin brother so much he wanted to be with him. Although we get some comfort from knowing they are now together, we still cannot describe the desperate feeling of loss we both have in our hearts, it is unbearable.

From that point, my wife and I both really struggled with our grief. My work were very good to me and gave me as much time off as I needed, but deep down all I really wanted to do was get back to work and keep busy.

I kept myself busy for a while, arranging the second funeral and writing letters to family and friends. Apart from close family we could not bring ourselves to pick up the phone to talk to people at this time, so we decided to write a letter to everyone explaining what had happened along

with the funeral details. We also decided we didn't want flowers at the funerals, instead we arranged a collection for Queen Charlottes Neonatal Unit in memory of our boys to hopefully help other babies have a chance of life. People were very generous and we raised over £6,000 in our boys' memory.

One thing I have learnt from our experience is that grief is an extremely unique and personal thing. Everyone copes with it in completely differently ways. Understanding this at the time was impossible though.

At the time, neither of us could see it, but looking back on things now it was as if we had hit a fork in the road on our grief journey. I wanted to take the left fork and my wife wanted to take the right. Sometimes I felt as if I was being pulled down her road, she would spend day after day crying at home. All she really wanted me to do was comfort her and talk about the boys, but for some reason I was unable to do either of these things. I was grieving too, but at the time she could not see that. It was as if she thought I didn't care and that I just wanted to get back to normal, whatever normal was? It wasn't that at all, I was constantly thinking about our boys, I just could not express it emotionally like she could. All I wanted to do was keep moving. I think I was scared of what might happen if I stopped and we both completely fell apart.

A few weeks later I eventually went back to work. The first day back in the office was very difficult. I arrived in the car park and I sat in my car for a good

10-15 minutes before I gained enough courage to enter the building. Walking though those doors was daunting. I wanted people to acknowledge our loss but at the same time I remember trying to avoid as many people as I could. I think I was scared what people would say, and how I would react to them. I went straight to my desk and tried to make myself look busy, as I normally would have been, but I just could not concentrate on anything. My mind kept wandering, thinking about the boys, how my wife was coping for the first day all on her own at home, and our relationship which at the time seemed to be steadily falling apart day by day. I wanted to go and get a cup of coffee, but didn't feel I was ready to be around people chatting about their weekends and the wonderful things they had been up to. Even worse would have been a silence as I entered the kitchen, I just couldn't face it. A few colleagues came over to my desk and expressed their condolences and told me it was nice to see me back at work. What shocked me the most was that the ones I expected to say something quite often didn't and the ones that I wouldn't have expected in a million years to mention it, seemed to make a special effort.

Soon after our loss we got in touch with many support groups including Tamba BSG and Sands. We went to a few group meetings and met other parents who had been through similar experiences. Personally I didn't find these groups my sort of thing, although I could see it was really helping my wife, so I continued to support her by

going along with her to them when I could. We also went to many different councillors before we found the Child Bereavement Charity, who we still see on a monthly basis now. I can say that this has got to have been the most help to us both in our times of need. The group sessions are nice to be able to hear other stories and help you realize you are not all alone and to know that there are other people going through similar losses to you, but being able to speak openly to a councillor who has been trained in understanding child bereavement and also the effect it has on your relationship is something I would recommend to anyone who has been through such a loss. On the other hand, I also now know how important it is to understand that we all grieve in very different ways, what may be helpful to one person is not always helpful to another, but it is only when you try all options available to you that you find out what works best for you as an individual.

We were dreading Christmas time with all the memories of what could have been if our boys had survived. We ended up having a very quiet one, just the two of us and it didn't actually turn out as bad as we first thought. The anniversary of our boys' birthdays is now fast approaching, which I am sure is going to be another very difficult time for us both, but at least our relationship has now pulled back together again and is stronger than ever thanks to the help of the Child Bereavement Charity, so we will at least be coping with it as best we can together.



## HELPING EACH OTHER WITH BEREAVEMENT

- The most important thing you can do is to keep talking honestly to each other through your pain. Recognise it will be difficult and that you won't always be able to relate to each other.
- Try not to judge each other's styles of grieving.
- You may have to spell out exactly what you want from your partner and how they can help you. Try not to be too confrontational when you do this. It is better to say 'I feel bad when you do this ... or say this ...' rather than 'You make me feel terrible when you do this ...' or direct accusations such as 'You don't care'.

- Your partner will appreciate any support you give them, even if they don't always thank you at the time.
- Touch and intimacy is important, but it does not need to be sexual. It takes time to feel emotionally and physically ready to get close again, whereas your partner may wish to express their love and seek comfort by making love. Discrepancies between partners' sexual needs can lead to you thinking your partner is insensitive, while they become resentful and even needier. If you think you are withholding intimacy for fear of initiating sex, you could talk about not going further than an agreed limit until you feel ready.

### A SURVIVING TWIN BABY

There is no correct moment to tell your surviving child about their twin, but the longer parents leave it, the more difficult it can be to find the perfect time and you may run the risk of someone else telling them first. Those children who have grown up not knowing about their identity often feel devastated and betrayed that they were never told. A gradual process of letting your child know they are a twin is often the best way. Think of it as a jigsaw puzzle, where you give them a piece at a time and they put it together at their own pace.

You may want to read stories about twins and explain that they too are a twin, but their brother or sister is no longer with you. Your child can ask questions in her own time. A good book for talking with your child about what it means to be a surviving twin is the children's book - 'Always My Twin' by Valerie Samuels. The story is told through the eyes of a young

girl whose twin sister dies shortly after their births and it is based on the author's own experience of losing a newborn twin daughter.

Parents often like to display photos, cuddly toys or other mementos in prominent places around the house so the surviving child can feel their twin is still part of the family, although you should be careful not to create a 'shrine' which idealises the lost child. Some families also like to include an object to represent the child in family photographs, for example a cuddly toy.

### SIBLINGS

Children often experience grief in a different way to adults. You may find it helps to use simple language when explaining what happened. Don't be afraid to say their brother or sister, or the babies in mummy's tummy, have 'died' – children often welcome having

a new word to understand an event that they have never experienced. You can use simple words, such as "death is what happens when the body stops working". Children tend to think very literally, so describing death as 'loss' is difficult for a child to comprehend and they may wonder why you aren't looking for them. There are also potential problems with describing death as 'God's will', as it may create a fear of religion.

Don't be surprised if your children ask the same question several times, while they try to process the information and understand the finality of death. Young children under six years old are not able to comprehend death is permanent and may be confused. Children often see

their family, and indeed the world, as revolving around them. They may think they caused the death or can control the future. Even children up to the age of eight years old may still hope that they can somehow undo the death, perhaps by being 'good'. Older children may want to know 'how' and 'why' it happened and be interested in all the small, and sometimes macabre details, including questions about the body and what happens at the burial or cremation.

Please don't think that there is a correct way for a child to grieve. As adults, we understand better what death means and can find it difficult to work through that. Children can seem more resilient and sometimes even uncaring. The child

## TALKING WITH MY SON ABOUT THE LOSS OF HIS TWIN

### JEANNE KIRKWOOD

My son Ben's twin brother Sam died eleven years ago when they were 15 months old. I have always replied to Ben's questions about Sam and death with simple honesty. I soon learned that was all he wanted for an answer – a simple one sentence reply. When Ben started nursery, he asked "Does Sam go to nursery in Heaven?" He wanted reassurance that Sam was doing the things he could do. Over the last few years, since Ben could talk, he has asked many questions. He understands about being sad when someone close to you dies. He knows they will not come back. He knows about rituals such as funerals and memory boxes.

At age 12, Ben can now decide

for himself if he wants to attend remembrance services for Sam. Sometimes he does and sometimes he decides not to. He can tell me when he feels sad about Sam dying. When someone we know is dying, I am able to tell Ben and prepare him.

I hope that because we were open in what we said when Sam first died, that it has become easier for both Ben and myself to talk about death with appropriate emotions. It also makes it easier for other family members to talk. During the last eleven years, Ben has learned important skills about dealing with bereavement that he will take with him into adulthood. We can both thank Sam for that.

bereavement charity, Winston's Wish, has observed that: "Adults could be said to wade with difficulty through rivers of grief, and may become stuck in the middle of a wide sea of grieving. For children, their grieving can seem more like leaping in and out of puddles. One minute, they may be sobbing, the next they are asking: 'What's for tea?' It does not mean they care any the less about what has happened." Allow them to be sad, but also encourage them to laugh, have fun and display normal childhood behaviour.

## GRANDPARENTS

The death of a baby also impacts upon many grandparents. They often feel sad and powerless that they cannot protect their children from the pain of

bereavement. Not only are grandparents often deeply affected by their children's grief, but they may also be upset about the death of their grandchildren and their own personal loss. Many grandparents of twins hope to play a special role in their grandchildren's upbringing - offering hands-on care for the babies when they're young, looking after them while the parents work or having the grandchildren to stay for a few nights. It is understandable that the loss of a grandchild can feel completely devastating.

It is also an unpleasant reminder of the grandparents' own mortality and they may feel guilty that it should have been them who died - not a young baby or child with their whole life ahead of them.

## GRANDPARENTS:

### SUPPORTING YOUR CHILDREN

When a baby dies, the responsibility for caring for the other siblings and supporting the parents through their grief often falls on grandparents. Grandparents are often expected to put aside their own feelings of bereavement and be a tower of strength for the entire family. Some suggestions for grandparents of twins to help them support you, as parents, are provided below:

- Be there for your children – hug them, let them cry, listen to them and call them often.
- Think carefully before giving advice – don't for example suggest that 'at least you have another one'.
- Support your children's grieving process, without judgement. Remember that everyone's bereavement is different – there is no right or wrong way to grieve.
- Offer practical help, such as making

meals with extra portions to store in the freezer, washing up or other household chores.

- Help look after the other grandchildren in the family, but remember that children value continuity - now is not the time to try out new routines or discipline techniques.
- Try to be patient if there are misunderstandings. Anger is a key phase of bereavement and your children may unintentionally direct their anger in your direction. Try not to take it personally - the death of a child tests all family relationships.
- Keep talking to them about their loss, even after several months have passed. Bereaved parents find it difficult to cope when people stop asking them how they are for fear of opening old wounds. Don't be afraid of asking how they're doing many years later, especially on difficult anniversaries.

## LETTING OTHERS KNOW HOW TO HELP YOU

If you've lost one or all of your twins, your friends and family can be a wonderful source of support. They may however feel helpless and be unsure what to say or do. They may say things to try to make you feel better, which unintentionally cause you to feel sad and angry. Please remember that they are not trying to be insensitive or hurt you; they simply do not understand your loss or what to do to help you.

## HOW CAN YOU HELP A BEREAVED PARENT OF TWINS?

Although you cannot do the one thing they most want – bring back the baby(ies) who have died – you can help. Small gestures let them know they're not alone and you're thinking about them. Bereaved parents continue to grieve for many years and it is important that you don't stop asking if they are ok, especially around birthdays, anniversaries, and other special days such as the surviving twin's first school day, their graduation and wedding. They will appreciate your support and kindness at these painful times.

## HELPING A BEREAVED PARENT:

### SOME IDEAS OF WHAT TO DO

- Approach the bereaved parent rather than waiting for them to come to you.
- Don't be frightened of their pain – remember that it's not catching.
- Make eye contact, gently touch them or offer a hug if it seems appropriate.
- Listen, without offering advice. Don't make comparisons with your own experiences of bereavement. This is their time to talk, and yours to listen.
- But also ... let them be silent. They don't always need to talk.
- Be available – try not to appear uncomfortable or guilty if your children are still alive and well.
- If you ask them how they are, make sure you have the time to listen to their answer – it's important they don't feel rushed or get the impression that you would rather be elsewhere.
- Write a letter of condolence to let them know you're thinking about them
- Offer practical help – take the other children to the park or look after them for a while, make a cup of tea, wash up, or bring food around.
- Invite them to social events, but understand if they feel they can't yet be around lots of other people.
- Understand that their appearance of doing well may be deceptive.
- Arrange a specific date to meet up, rather than vague comments that 'we should get together'.
- Don't downplay their loss – "At least you've got another one", "Try to think positively" or "They have gone to a better place" are not helpful comments to somebody who has just lost their babies.
- Suggest going for a walk with them, as conversation is easier when you walk together.
- Tell the father you are sorry too – don't forget him and don't tell him to "stay strong".
- It is never too late to say something – even several years later, you can always ask how they are and apologise for not being there at the time.

*Adapted from: Hurcombe (2004); and Multiple Births: Bereavement Support website, Canada*

# REMEMBERING

## CREATING MEMORIES

There is an old Russian proverb – “you live as long as you are remembered”. Remembering is a bittersweet painful process, but it is normal to keep remembering your child. There are countless ways to remember.

## COPING WITH ANNIVERSARIES

Just when you feel like you’re starting to cope with everyday life, the memories and emotions of bereavement are often reawakened by anniversaries, birthdays and other landmark days – Christmas, New Years, Mother’s Day and Father’s

“ THE RETURN OF YOUR GRIEF CAN FEEL LIKE A SET-BACK, BUT TRY TO VIEW YOUR SADNESS AS A REFLECTION OF HOW MUCH YOU LOVED YOUR BABIES OR CHILD ”

# REMEMBRANCE

## SOME IDEAS

Parents often like to find ways to remember their babies and this can be an important part of the healing process. Here are some remembrance ideas:

- Plant a tree, a flowering bush or tub of flowers in their memory. Look for a tree or flower that has meaning to you, for example it blooms around your babies’ birthday.
- Create a special place for remembering, for example with a bird bath, small statue, garden bench or plaque.
- Create a scrapbook of your memories, photos, special dates etc.
- Make a special memory box of all the items that remind you of them.
- Make some of your baby’s favourite clothes into a quilt, wall hanging or a little pillow.
- Commission a sketch, portrait or

a sculpture. Some artists specialise in recreating paintings of the family together by looking at photos, including ultrasound images.

- Remember your babies in jewellery – engrave their name, get a special piece designed in their memory (such as two bracelets or rings interlinked, or an item with their birthstone on it), or put their photo/lock of hair in a locket.
- Name a star after them ([www.starregistry.com](http://www.starregistry.com))
- Fundraising for causes related to your baby or babies’ death.
- Start a memorial webpage, for example [www.gonetoosoon.org](http://www.gonetoosoon.org)
- Create a scholarship or a charitable foundation.
- Write poetry, articles or a book, or compose a song.
- Framed tapestry with their name, date of birth and death on.

# BIRTHDAYS AND ANNIVERSARIES:

## MARKING THE DAY

Some parents prefer to remember their loved ones quietly, while others like to have a more formal act of remembrance. Children (especially surviving twins) often need to talk about their lost brother or sister and know that they have not been forgotten. You know best what is suitable for your family. Some ideas for marking the day include:

- Visiting the grave or where the ashes were scattered.
- Returning to a place with special memories.

- Leave something in the special place – a toy, balloons, flowers, messages, birthday cake, little Christmas tree or decorations.
- Hold a small ceremony with music, poems, and stories.
- Lighting candles.
- Saying a prayer.
- Releasing balloons (with messages or drawings on), butterflies, birds or a kite.
- Listening to a favourite piece of music.
- Birthday tea/party and cake.
- Going for a walk.

Day. Especially during the year after their death, there will be a lot of ‘firsts’ where you will be reminded of your loss. The return of your grief can feel like a set-back, but try to view your sadness as a reflection of how much you loved your babies or child, rather than how well you are coping (or not).

Birthdays can be particularly difficult if one twin died at birth, while the other survived. Celebrating another year of one child’s life, while remembering the other, is a very difficult balance that some parents get round by holding the birthday and remembrance a few days

apart or allocating some time during the day to specifically remember the child who has died. You may also want to ask a family member or close friend to help you with the birthday celebrations, in case you need to have a little time by yourself if you suddenly feel sad.

You may continue to feel a great sense of loss at the different stages of life your child cannot experience – university graduations, their wedding day, and the loss of your future grandchildren by that child.

## CARING FOR A SURVIVING BABY

Looking after a newborn is an emotionally and physically exhausting time, without the added challenge of coping with your grief at losing his or her twin. Do speak to your doctor or health visitor if you are struggling to cope and think you are suffering from postnatal depression, which is very common for parents who have lost one of their twins. Please don't feel you have to suffer in silence. PND can be treated, either by medication (antidepressants), psychotherapies or 'talking treatments'. Early treatment is vital and it is important to get help, as untreated PND causes distress to you, your partner and your family. For more information on how to recognise the symptoms, diagnosis and treatment, please see Tamba's Postnatal Depression: A Guide for Mothers of Multiples can be downloaded from [www.tamba.org.uk](http://www.tamba.org.uk)

Some parents feel helpless; scared of bonding with their surviving baby in case they lose them too. This fear is natural, but you know deep in your heart the importance of not shutting them out. It is essential that as your children get older, they do not get the impression, however unjustified it may be, that you wish they had died instead or that it was their fault. Try to keep reassuring them they are loved and wanted.

Another common, and understandable, response is to feel

protective of the surviving twin's health and safety. You are likely to feel anxious after the trauma of losing your baby, but be careful not to pass on your worries to the extent that as your child grows up, they feel vulnerable and lack confidence.

Parents are often concerned about how much their surviving child might be affected by the loss of their twin. Surviving twins may imagine that their lost brother or sister would have been perfect – would have understood him and protected him. Some surviving twins seek to make up for their parents' and their own loss by trying to 'live for two'.

At the other end of the spectrum, some surviving children may feel disheartened by living in their twin's shadow and need extra encouragement and support. It can be hard for surviving twins, with all their natural childhood flaws, tempers and tantrums, to live up to an idealised version of their dead brother or sister. While it is important for your surviving twin that his brother or sister is remembered, honoured and missed, try to reassure your surviving child that they are valued too.

As your child gets older, let them know that they can always talk to you about their twin. Your child may have lots of questions and this should be encouraged, but at their own pace. It might not necessarily be at the moment that is best for you. When they do want to talk, try to stop what you are doing and be available for them. There are no correct answers, just honest ones (even a simple 'I don't know'). Reassure them they are not to blame – they did not cause the death of their twin, they could not have prevented it and they shouldn't feel guilty for still being here.

## MY STORY OF LOSING ONE TWIN DURING PREGNANCY: KAREN CARTER

"It's twins," the doctor confirmed. I was equally thrilled and shocked. James, my husband, thought I was playing a practical joke when I relayed the news. Sophie and Thomas, then aged six and four, said "Great! A baby for each of us".

I spent the next five months meticulously planning for the great event which would double our family in one go - practising at being super mum. It was exhilarating.

Then at 33 weeks I had another routine scan. I knew by the doctor's tone of voice that something was not right, but nothing prepared me for the shock of discovering that Olivia, one of our beloved identical twin girls, had died.

Megan and Olivia were delivered by caesarean section at 7pm the next day. Megan was rushed off to the special care unit that night and we were really only properly introduced the next morning.

I had Olivia for the night but not the living baby and the twins I had hoped for. Olivia (and all the dreams that went with her) had gone, without me even being able to grasp what I had lost.

How do you celebrate one life and grieve for another at the same time? We had to do that at Megan's birth and Olivia's funeral. It was a time of great confusion when I did not really know what to feel. We sent out a birth announcement with Megan's details and a poem for Olivia (it was one of the few things we could do for both of them).

The first year was a struggle. I talked to friends and family who were all very

supportive, but none of them had been through anything similar. What helped me most was becoming a bereavement support group representative for Tamba. Talking to other bereaved families has been a privilege. I had lost so much, but what I gained was experience and what I wanted for the future was to create something good out of something bad.

For anyone going through a similar experience I would say:

- Do take photographs and keep any reminders of the baby or babies that you have lost - even if they are not precious to you now, it is very likely that they will become so in the future;
- Do allow yourself time to grieve even though this may be very difficult;
- At some point what you are feeling now will change and become more bearable.

Eight years on and how is it now? I have learnt to accommodate Olivia's loss and it is not, for the most part, so overwhelming and incapacitating as it was at the beginning. However if I get into my Tardis and catapult myself back to that moment, the same feelings are still there. We never had the opportunity to get to know Olivia and that will always be a source of sadness.

I will now allow myself to stroll down the 'What If Avenue', something I could not do for a long time. Megan occasionally joins me there and we imagine a different life with Olivia. It is not enough, but the memory of what could have been is something that we cherish.

## RETURNING TO WORK

Bereaved parents often wonder when the right time is to return to work, but there is no timetable for grief. Work can provide a temporary relief from the overwhelming grief you feel at home. Men, in particular, prefer to keep busy and their place of work may be a refuge, somewhere that feels normal and routine. However, if you are returning to work when you are not

“ IF YOU ARE RETURNING TO WORK WHEN YOU ARE NOT EMOTIONALLY READY, YOU WILL NOT BE DOING YOURSELF OR YOUR EMPLOYER ANY FAVOURS. ”

emotionally ready, you will not be doing yourself or your employer any favours. You may need to return for financial reasons, to protect your job, or to keep your clients (if you are self-employed). Perhaps you worry that you are letting people down at work. But please remember that it can take some time to come to terms with your grief and you may lack motivation or be less effective for a while. Ideally you should return when you think you can cope and function properly.

## RETURNING TO WORK:

### SOME SUGGESTIONS

#### You may want to...

- Let your employer know how you are coping and discuss the best possible way to return to work.
- Consider the possibility of working flexi- or part-time for a while.
- Tell a trusted work colleague what happened if you don't feel comfortable talking to others about your loss, so they can act as a buffer and explain how you are doing. You don't have to tell your story to people if you don't want – a simple 'thank you' when they tell you how sorry they are is enough.
- Talk to your manager or colleagues if you're having trouble concentrating or worried that your work might be suffering – they could review your work for a short period of time. Don't be afraid of asking for help.
- Briefly explain what has happened and excuse yourself if you think you are going to break down in a meeting. People will understand.
- Let your work know if you want to be included in regular email correspondence while you are away from the office.
- Take each day as it comes – your confidence will slowly return.
- If you have lost a child suddenly and in traumatic circumstances, you might want to ask your grief counsellor to go into your workplace and talk to your colleagues (or your employer could arrange for this).

## SUBSEQUENT PREGNANCIES

There is no right time to start trying again for another baby. Although you may wish to conceive again soon, it takes some time to feel emotionally and physically ready. This waiting period may be three months, or it may be two years. Only you and your partner will know when is appropriate, but you need to give yourself some time to grieve and to reach a point where you recognise that another baby will not replace what you have lost. You will probably never be truly 'ready', but you will instinctively know when you want to start trying again.

If your twins were conceived using fertility treatment, you may be justifiably concerned about whether you will be able to have any more children. Although

you may be conscious of time slipping away from you, you should also consider whether you are emotionally strong enough to cope with the disappointment of not conceiving for some time.

Finding out you are pregnant again is exciting, but can also be confusing. As well as joy, you may feel frightened for your pregnancy. Some parents try to protect themselves from the fear, by putting up mental barriers (ignoring the pregnancy, trying not to dream about the future). You may worry that if you become too attached, you will get hurt again. It is also not unusual to feel guilty that you are betraying the babies you lost by moving on with your life. Your partner may also feel helpless and worried about the pregnancy. You are bound to be anxious, but please try to remember that most pregnancies have a positive outcome.

Having a new baby will bring conflicting emotions and it can take some

## DURING THE NEXT PREGNANCY

### SOME IDEAS TO HELP YOU COPE

#### You may want to ...

- Consider how you will respond when people ask you 'Is this your first pregnancy?'
- Do something different to distinguish the pregnancy from your previous one – this may be different pregnancy clothes, changes in diet or baby items.
- Write down your feelings, for example by keeping a diary.
- Have a partner, trusted family member or friend with you for your antenatal appointments.
- Join a support group for women who have been through subsequent pregnancies, for example the Stillbirth

and Neonatal Death charity, Sands, can offer support through this exciting but worrying time.

- Ask for a 'tear drop sticker' (from Sands) to be placed on your hospital notes, so that staff are aware that you have experienced a death of a baby.
- Think about whether you want to return to the same hospital unit – this will depend not just upon logistics, but whether you have built up relationships of trust with the hospital or not.
- Don't be afraid to ask as many questions as you need to reassure yourself, including asking for any extra scans or monitoring.
- Take one day at a time.

time to adjust to the reality of a happy outcome. If your baby or babies died soon after the birth or in the first year, it may take longer to relax. Parents do not always immediately bond with their subsequent baby – this does not mean you are a bad mother; you just need some time to get to know them and love them. If you're struggling to cope and think you might be suffering from postnatal depression (PND), please talk to your doctor or health visitor. PND is quite common for mothers, especially those who have been bereaved.

You may also be surprised at your

sadness at the loss of the experience of parenting twins and wonder what it would have been like to have been a mother to more than one baby. Although you may look at your new baby and imagine what could have been, you will soon get to know their unique personality and love them for themselves. Your lost babies or child will always be part of your family and many bereaved parents of twins like to include their subsequent children in the process of remembering – taking them to see the grave, releasing balloons on the anniversary of their birth/death, and talking about their brothers or sisters.

“ALTHOUGH YOU MAY LOOK AT YOUR NEW BABY AND IMAGINE WHAT COULD HAVE BEEN, YOU WILL SOON GET TO KNOW THEIR UNIQUE PERSONALITY AND LOVE THEM FOR THEMSELVES.”

## THE STORY OF LOSING ONE OF MY TWIN BABIES AND MY SUBSEQUENT PREGNANCY: NICKY

My twin pregnancy was my first. I was extremely fortunate to have an incredibly easy pregnancy and suffered nothing except mind-boggling tiredness at the beginning before we even knew it was twins. No twins run in the family so it was totally unexpected, but the pregnancy itself was perfectly straightforward and unproblematic. They were non-identical and grew within millimetres of each other until the 35 week scan when one was discovered not to have grown quite as much, but not a difference that was of concern. However, following that scan, the midwife took blood from me as I complained about itchy hands and feet, which were apparently key signs of cholestasis (when your liver stops working properly due to the pregnancy).

We turned up the next day to get the results, not unduly concerned, but my results were high and I had to stay there until the doctors decided what was best to do. I was warned that I would be induced the following week, but whilst waiting I was put on a foetal heart rate monitor and the consultant decided he was not happy with one twin's heart rate and I would have a c-section that day. The midwives did not seem to think there was much problem with the reading and everyone assumed the cholestasis was affecting one twin.

Following my c- section, my eldest, Pippa, was whisked off to SCBU as she was anaemic and I was told she would be back within the hour. I was wheeled up to the ward with Rowan. Unbeknownst to me, real dramas unfolded in SCBU. Every time Pippa was given blood, her heart stopped. She was resuscitated successfully, but still needed more blood to carry the essential amount of oxygen to live. When she was given the blood again, the same thing happened. This continued for hours until finally I was informed and she was given to us to drift off herself.

The medical staff were perplexed until blood was taken from me the following day and revealed a very high level of foetal blood in my blood. She had had a small foetal maternal haemorrhage some time ago and had been losing small amounts of blood over a long period of time, which caused her veins to collapse. Her heart was not strong enough to cope with the amount of blood she needed to stay alive.

We always wanted a family of two and we decided we didn't want to have too big an age gap. However my emotions were still pretty raw and I was very anxious about getting pregnant, coping with being pregnant, conceiving twins again, having a boy or a girl, and also managing to actually

have a healthy baby at the end. I was desperate for a girl, having lost one.

Through Tamba BSG I was contacted by a lady who had another pregnancy following losing a twin in her previous pregnancy. It was great to talk to someone who could totally understand my fears. She helped me prepare for what I might feel and what it was worth asking for medically. Once I was pregnant, I actually found it very hard to tell people. I didn't want them to congratulate me as I hadn't managed to successfully produce a healthy child yet. I found it hard dealing with their excitement and support when I was not that excited because I could not trust that it would work out ok.

I was determined to go back to the

questions about the last pregnancy. I hated this. After the second time, I kicked up a fuss and made it really clear that I only wanted to be seen by particular midwives in the local practice and at the hospital. However my first scan and 20 week scan were still done by those who did not know our history and I felt really uncomfortable with it, but I couldn't control those incidences.

My consultant was fantastic. He took us on after being the one on duty when Pippa died. I needed constant reassurance that everything was going ok. He told us right after the first pregnancy that we would not have twins again and we would not have a foetal maternal haemorrhage, but there was no way I could believe

“ IT WAS GREAT TO TALK TO SOMEONE WHO COULD TOTALLY UNDERSTAND MY FEARS. ”

same hospital with the same consultant. I wanted people who knew my history when I had an appointment, and who were understanding without me having to explain everything. I know that some people are different and want to be in a different location with new medical staff so there are no reminders.

I was pleased to have the Sands teardrop on my file so people would know that there had been a loss previously, but despite this I still encountered a few occasions when medical staff were not prepared. I sat and waited whilst midwives read my file, knowing what they were reading and that I would have to answer

him. I needed medical proof as often as possible. We got our first scan at 9 weeks and had the relief that it was a singleton pregnancy. I then had appointments every two weeks, alternating between my midwife at the local practice and a scan, blood test and the consultant at the hospital the next time. They tested for foetal blood in my blood. After every hospital visit, my fears and anxieties would be allayed. However it didn't last long as I knew, oh so well, how things could appear to be going smoothly but actually go very wrong, very quickly and no one could tell. So I remained very emotional and anxious throughout

the pregnancy, constantly looking forward and dreading the next hospital appointment.

A couple of times I was recalled as the blood test results were a bit high and that was very distressing, but each time the following test would be fine. However, other people, (especially if they had a very difficult multiple pregnancy and had been in and out of hospital a lot and had enormous amount of medical intervention) may well actually want to be left alone and just have the regular amount of scans and midwife visits and just want a "normal" pregnancy.

I desperately needed to know the sex of the baby as I knew I would be devastated if it was a boy. I wanted to be delighted at the birth that I had a healthy baby, not in tears because it wasn't the girl I hoped and dreamed of. However, we found out at the 20 week scan that we were having another boy and it took me months to get used to it, actually want it or like it. Fortunately I came through well before the birth and couldn't have loved him more, but there was a fair while when I didn't really want this boy baby.

I had been recommended to have a elective c-section at the beginning and I booked one in. However, emotionally I really wanted to try a natural birth as I felt that I wouldn't be a real woman if I couldn't give birth to a child properly. However, as I neared my due date I got even more anxious. The idea of a fixed date really helped, as I knew when the uncertainties would end. There was also a possibility my choleostasis would return and it felt to me that the longer he stayed in there, the more

chance of things going wrong. So, at 37 weeks, we had an elective c-section. I tried to get the midwife who helped us after Rowan and Pippa to be there, but unfortunately she couldn't get childcare. She warned the people in theatre, so they were very kind. It was distressing being in the same theatre, waiting in the same way that we did 18 months before, but we managed it. The beautiful healthy baby boy we had was worth all the anxiety, distress and emotion of the pregnancy.

I had to stay in hospital following the c-section, but it was much better than expected. I had not stayed in the postnatal ward for more than a couple of hours the last time and I was in a different part that did not have any sad memories for me. The other ladies in the ward did not know my history and I was pleased they just took it that Finn was my second child. I was prepared to be very emotional, get postnatal depression, and really need lots of support, but I didn't really. I found the pregnancy the hardest bit as I couldn't believe anyone who told me it would be all right, because that was what everyone said the first time - and it wasn't. After our healthy son was born, that stress vanished and I just had to deal with the "normal" stresses of a newborn, sleep, feeding and entertaining a toddler at the same time!

We will never forget Pippa and both boys know that she is their sister, but having another child reasonably close together has helped us feel like the family we wanted to be. It was hard, but definitely worth it.

## REMEMBERING OUR TWINS

### SHARON DARKE

#### 1 YEAR ON: CHARLIE & JOSHUA'S 1ST BIRTHDAY

It was Charlie and Joshua's first birthday two days ago. In some respects the year has gone quickly. I am now able to think of my twin boys with a smile. I have such wonderful memories of them both that never fade. At times however, I feel as sad as I ever did. I have been lucky enough to have had another baby. When my boys were taken from me, the only reason I had to keep going was that I would be a mum again soon. Getting pregnant again so quickly definitely helped me in the grieving process although I had nine months of continuous worry. The pregnancy was not very enjoyable, the only time I was happy was when she was kicking – and luckily she was a very active baby. I think she knew that I needed her to be.

When Jessica Louise was born she looked very much like her brothers Charlie and Joshua with her dark curly hair and her big eyes. Some of the expressions that she pulls remind me so

much of Joshua. We love her so much; she could not be more wanted. I often find myself wondering however what it would have been like if our twins had survived, bathing, feeding, changing two babies. I will never know. Jessica will never know her two wonderful older brothers but they will be part of her life as she grows older and we show her the photographs and the video of them both. It gives me comfort when Jessica wears their clothes and uses their car seat, bath, etc that were originally bought for Charlie and Joshua.

On Charlie and Joshua's first birthday, we took Jessica to the cemetery for the first time along with flowers for the boys. I love them and miss them so much. We had very few acknowledgements of their birthday from family and friends, although I received cards and letters from people that I have met and made friends with through Sands and Tamba, who obviously know how it feels. Charlie and Joshua's grandparents also visited

their grave with flowers. My mum bought us a lovely forget-me-not picture. However, none of my friends have even mentioned it. I don't think they realise how much it hurts. I only wanted a letter or a phone call, which said they were 'thinking of us'. I think now that

Jessica has been born they think that the hurt we feel from losing our boys will disappear. Only time makes our loss more bearable but I will never understand why they were taken from us.

I still often think about the hospital in Staffordshire where they were born and wonder who remembers us and our twins. We are hoping to have a trip up there to show off our new daughter. I am in touch with one of the nurses who cared for Charlie and Joshua. I received a lovely card from her on the 13th, telling us she will always remember our baby boys Charlie and Joshua Darke.

I still find it very hard when I see twins. I seem to have seen more sets of twins in the past year than ever before. I find myself peering into double pushchairs and prams. It is still baby twins that affect me most – I think because they were babies when they died, even though they should be a year now. A lady in the next bed to me in hospital was expecting twins and having a caesarean the following day. She was 38 weeks. I found myself wondering why she had got that far when I only got to 26 weeks. I still have no explanation.

I wanted to write something for the Tamba newsletter to give others hope [This 1 year story was originally published in Tamba's newsletter]. Also to help people realise that you can be happy again. We are so happy and proud of our new baby daughter. This time last year I never thought I would smile again. I am sure we still have a

long way to go and will still find certain days and times of the year difficult, but having Jessica has definitely eased the pain. I hope that Charlie and Joshua are looking down on the three of us, looking after us all.

#### 5 YEARS ON: LETTER TO CHARLIE AND JOSHUA 13 SEPTEMBER 2004

Dear Charlie and Joshua,  
It is five years since you were born. You should both be starting school now. It seems longer ago now, but at other times not as long as five years. You have a younger sister Jessica who is 4 and talks about you regularly and a 2 year old brother Samuel, who doesn't really understand yet, but knows that you are Mummy's babies.

Jessica and Samuel both love bringing you flowers to the cemetery. I love to see them plodding around in the cemetery in their Wellingtons. We have to take it in turns to poke the flowers into the holes. Jessica loves to help me choose the flowers – always "boys' colours" (not pink).

Five years ago when you were born you gave me so many special and beautiful memories that will always stay with me. When you died I honestly thought I could never be happy again. I thought that Christmas would always be awful, however my grief has changed so much. Since having Jessica and Samuel my life is happy again and I get so much enjoyment out of them both, but there is always an empty space where you both should be. Occasionally I

“ I OFTEN FIND MYSELF WONDERING WHAT IT WOULD HAVE BEEN LIKE IF OUR TWINS HAD SURVIVED, BATHING, FEEDING, CHANGING TWO BABIES. I WILL NEVER KNOW. ”



feel guilty for enjoying life so much again, but my whole life is my children; both of you, Jessica and Samuel. I do everything I can to keep your memory alive, but it is increasingly difficult as time goes on.

There are people who know me now who do not know about the two of you because sometimes it is not appropriate to tell people and so often people do not know what to say. However all of my friends that are special to me know all about you. People rarely speak about you anymore unless I initiate it, except Jessica, my

“ YOU STILL AND ALWAYS WILL PLAY A BIG PART OF OUR EVERYDAY LIVES. YOUR PICTURES ARE ALL UP IN OUR HOUSE. YOU ARE BOTH IN ONE SIDE OF MY LOCKET WITH JESSICA AND SAMUEL IN THE OTHER SIDE. I HAVE KEY RINGS WITH BOTH OF YOUR NAMES AND PHOTOS IN AND I STILL COLLECT THINGS FOR MY VERY FULL TREASURE BOX AND SCRAPBOOKS. ”

parents and a few friends, as well as the Sands and Tamba friends I have met through losing you. I think some people even forget it has happened

most of the time, which gets worse as the time goes on.

I still think of you both as babies, not as five year old boys. I often wonder what you would be like if you had lived. I wonder if one of you would have been like Jess and the other like Samuel. I used to think that Charlie would have been like Samuel and Joshua like Jessica when Samuel was a baby, but recently I have wondered if it is not the other way round. Perhaps you would have been different altogether.

I see twins all the time and it still affects me. I still don't understand why so many other twins lived and you did not. I often hear stories of premature babies of the same gestation that have lived and I feel jealous, or tales of people's labour that was stopped and feel envious as their babies survived.

I have been heavily involved in Tamba and Sands since you both died and will continue to do so for the foreseeable future. It feels like a time that can be devoted just for you. Your Daddy has become more involved recently and has just taken over as Oxfordshire Sands treasurer. I have organised group meetings, meeting up with people who have lost babies as well as taking phone calls from people also. Hopefully I help

people, just as those who spoke to me helped me when you died.

Jessica is at the age where she is asking lots of questions at the moment. It is really difficult to explain to her where you both are. She doesn't really understand the connection of the cemetery. Yesterday she said, "It's such a shame that Charlie and Joshua died". I love her comments, as they are so innocent.

You still and always will play a big part of our everyday lives. Your pictures are all up in our house. You are both in one side of my locket with Jessica and Samuel in the other side. I have key rings with both of your names and photos in and I still collect things for my very full treasure box and scrapbooks. We go to the remembrance services and light candles for you both and regularly go to the cemetery.

I never deny your existence. I would love to talk about both of you all the time and love it when somebody asks about you.

We love you now and always and miss you so much.

*Love Mummy, Daddy,  
Jessica & Samuel xxxxx*

### 10 YEARS ON: CHARLIE AND JOSHUA'S 10TH BIRTHDAY.

Dear Charlie and Joshua,  
It is now 10 years since the day I had you. Sometimes it feels like a lifetime ago while at other times it feels like only yesterday. You would both be going into year 5 this year. It's hard to

imagine what it would be like if you had lived. I often wonder would you have been like Jessica or Samuel or maybe different altogether. Samuel loves sport, particularly football, what would you two have been in to? What about school? Jess and Samuel love Maths, what subjects would you have both liked?

I love to talk about you both and feel really proud that I had identical twin boys. Jessica and Samuel often talk about you and I can sometimes hear them telling their friends all about you both. "These are my brothers Charlie and Joshua and they died because they were too small." We have photos of you all around our house- you are and always will be a massive part of our family. It makes me so happy when people talk to me about you both, although it's mainly family now unless I initiate the conversation.

I am still heavily involved with Sands and Tamba bereavement group. I mostly chat on the phone and at meetings to bereaved parents. I remember feeling so relieved when I spoke to someone who had lost a baby when you both died. When I speak to people who have just lost their baby or babies I can often feel their pain as it takes me right back to when we lost you. I still feel that the group meetings help me as I get a chance to talk about you both. Time is a healer, although I didn't want to hear that at the time of losing you. I can think of you and talk about you now with happiness and I really appreciate that I had you both for the short time that I did. I would never change any of that and love the fact

that I got to know your little characters while you were alive. Also I am so pleased that our family and friends got to meet you as well.

One of the most important things for me is that I feel I must keep your memory alive. It is easy within our family but more difficult in the outside world. I always want people to know that I have got four children and that is more difficult as time goes on. However you will always be part of our family.

This year for your 10th anniversary we have decided to raise some money for Sands and Tamba as these were the two charities that were absolutely paramount in helping me to deal with my grief. On your 10th birthday we

going to go on a barge for a day to celebrate your short lives. We are going to be on a friend's boat which is named 'Willow' after their baby girl that died, which makes it even more special. Hopefully we will be able to spend the day relaxing on the boat (well maybe not Daddy and Granddad) so that we are ready for the challenge. Jessica and Samuel are going to help me make and decorate a birthday cake for you that we will have on the boat.

I love you both and miss you as much as ever.

*Love Mummy xxxxxxxxxxx*

[We had the perfect weather for our ten mile walk on the twins 10th

**“ ON YOUR 10TH BIRTHDAY WE ARE GOING TO COME TO THE CEMETERY IN HOOK NORTON TO BRING FLOWERS AND WE ARE GOING TO RELEASE 10 BALLOONS IN YOUR MEMORY.”**

are going to come to the cemetery in Hook Norton to bring flowers and we are going to release 10 balloons in your memory. We will then walk the distance of 10 miles from the cemetery to our home in Banbury, one mile for each year since you died. Daddy, I, Jessica and Samuel will be joined by both Grandmas and Granddads and Uncle Neil to walk the distance of 10 miles together as a family. We are hoping for some sunshine!

The day before our walk we are

birthday and all completed the walk (including Samuel and Jessica). It took us four and a half hours and we raised just over £1000 to split between Sands and Tamba bereavement group. The day before on the barge was a glorious sunny day and we had a lovely relaxing time in preparation for the walk. The twins 10th birthday was certainly a weekend to remember.]

## AND FINALLY...

If you have recently lost your twin(s), you probably cannot imagine ever being able to accept your loss. Acceptance is not something that suddenly happens – it takes years to finally reach the stage where you have learned to live with your loss. It does not mean forgetting, nor is it simply 'getting over it'. It is much more complex - the memory becomes part of who you are. But just when you think

you are doing well, you may find yourself back at square one, just trying to make it through the day again. Please remember that it is normal to have good days and bad days.

There is no shame in asking for help, even many years down the line. Tamba's BSG are here for you. Keep taking care of yourself. When some happiness finds its way back into your life and you start to feel hope for the future, try not to feel guilty. We hope it does, and wish you well.

*I would like to take this opportunity to thank Erika for all the hard work she has put into researching and writing this booklet. I would also like to take the opportunity to thank the volunteer befrienders for all the time and effort they give to the Tamba Bereavement*

*Support Group and for allowing us to use their stories.*

*Carol Clay / Group coordinator*

## ACKNOWLEDGEMENTS

Special thanks go to Carol Clay, Tamba's Twinline and Supports Group Coordinator, for her help in coordinating and overseeing the production of this booklet.

Thanks also to Judith Schott and Alix Henley from the Stillbirth and Neonatal Death Society for reading the booklet and providing some very useful suggestions.

We would very much like to thank the following parents for sharing their personal stories and providing ideas, suggestions and corrections on the drafts of this guide: Aisha Carroll, Karen Carter, Nicky Chester, Sharon Darke, Matt Froud, Jay Harper, Jeanne Reilly, Clare Norman and Jenny Wightwick.

## RECOMMENDED READING

Hayton, A. (1998) *Not Out Of Mind: Prayer When a Baby Dies*, Wren Publications: St Albans.

Hurcombe, L. (2004) *Losing a Child: Explorations in Grief*, Sheldon Press: London.

Kohner, N. And Henley, A. (2009 ed.), *When a Baby Dies: the Experience of Late Miscarriage, Stillbirth and Neonatal Death*, Routledge: Abingdon.

Multiple Births Foundation (2007) *When a Twin or Triplet Dies: A Booklet for Bereaved Parents and Twins*, MBF: London.

Sandbank, A. (1999) *Twin and Triplet Psychology*, Routledge: London.

Sands (2010) *Saying Goodbye to Your Baby: For Parents who have had a Late Miscarriage, Stillbirth or Neonatal Death*, Sands: London.

Woodward, J. (2009) *The Lone Twin: Understanding Twin Bereavement and Loss*, Revised Edition, Free Association Books: London.

## HOW TO GET HELP – ORGANISATIONS OFFERING BEREAVEMENT HELP

### The Twins and Multiple Births Association Bereavement Support Group (TAMBA)

2 The Willows, Gardner Road, Guildford, Surrey, GU1 4PG  
Admin: 01483 304442  
Twinline: 0800 138 0509  
[www.tamba.org.uk/netcommunity/bsg](http://www.tamba.org.uk/netcommunity/bsg)

### ARC

(Antenatal Results and Choice)  
73 Charlotte Street, London, W1T 4PN.  
Helpline: 020 7631 0285 (10am – 5.30pm)  
[www.arc-uk.org](http://www.arc-uk.org)

### BLISS

(For babies born too soon, too small, too sick)  
9 Holyrood Street, London, SE1 2EL.  
Family Support Helpline (freephone): 0500 618 140  
[www.bliss.org.uk](http://www.bliss.org.uk)

### Child Bereavement Charity

Aston House, High Street, West Wycombe, Bucks, HP14 3AG  
Tel: 01494 446648  
[www.childbereavement.org.uk](http://www.childbereavement.org.uk)

### Child Death Helpline

Telephone: 0800 282986.  
Open 7pm-10pm every evening  
10am-1pm on Monday-Friday  
1pm-6pm on Tuesday and Wednesday  
[www.childdeathhelpline.org.uk](http://www.childdeathhelpline.org.uk)

### Compassionate Friends

(Offers friendship to grieving parents who have lost a child of any age through illness, accident, murder or suicide)  
53 North Street, Bristol, BS3 1EN  
Helpline: 0845 123 2304  
(10am-4pm; 7pm-10pm everyday)  
[www.tcf.org.uk](http://www.tcf.org.uk)

### CRUSE

(Offers a service of counselling, advice and opportunities for social contact to all bereaved people).  
Helpline: 0844 477 9400  
[www.crusebereavementcare.org.uk](http://www.crusebereavementcare.org.uk)  
Young people aged between 12 and 18 years should call 0800 808 1677

### Foundation for the Study of Infant Death (SIDS)

Artillery House, 11-19 Artillery Row, London, SW1P 1RT  
Helpline: 0808 802 6868 (10am-6pm Monday to Friday; 6pm-11pm everyday)  
[www.sids.org.uk](http://www.sids.org.uk)

### The Grandparents Association

Moot House, The Stow, Harlow, Essex, CM203AG  
Tel: 0845 4349585.  
(10am-4pm Monday to Friday)  
[www.grandparents-association.org.uk](http://www.grandparents-association.org.uk)

### Lone Twin Network

(Offers a network of contacts and support to adults whose twin has died at whatever stage of life)  
PO Box 5653, Birmingham, B29 7JY  
[www.lonetwinnetwork.org.uk/](http://www.lonetwinnetwork.org.uk/)

### Miscarriage Association

(Includes Ectopic Pregnancy Support Network)  
c/o Clayton Hospital, Northgate, Wakefield, WF1 3JS  
Helpline: 01924 200 799  
(9am-4pm weekdays)  
Scottish helpline: 0131 334 8883  
[www.miscarriageassociation.org.uk](http://www.miscarriageassociation.org.uk)

### Multiple Births Foundation

Hammersmith House, Level 4, Queen Charlotte's and Chelsea Hospital, Ducane Road, Hammersmith, London, W12 0HS  
Tel: 020 8383 3519  
[www.multiplebirths.org.uk](http://www.multiplebirths.org.uk)

### Stillbirth and Neonatal Death Society (Sands)

28 Portland Place, London, W1N 4DE  
Telephone: 020 7436 5881  
(9.30am – 5.30pm Monday to Friday; and 6pm-10pm Tuesday and Thursday)  
[www.uk-sands.org](http://www.uk-sands.org)

### Winston's Wish

(For children who have been bereaved)  
Helpline: 08452 030405  
(9am-5pm weekdays)  
[www.winstonswish.org.uk](http://www.winstonswish.org.uk)

This booklet has been printed and circulated with donations from:

**Sharon and Dominic Darke**

Sharon, Dominic and their families did a sponsored 10 mile walk in celebration of what would have been the 10th birthday of their beloved twin sons Charlie and Joshua.

See page 49 for the full story of how they celebrated the birthday.

**Caroline and Gary Clark**

Caroline and her running club along with their coach Marika organised a sponsored breakfast run in memory of their beloved twin sons Rhys and Sean.

Tamba BSG is funded almost entirely from voluntary donations and your support will make a vital difference to our work with bereaved families.

If you would be interested in finding ways to help the BSG please contact Carol Clay 01483 304442

You can donate by going to our website  
[www.tamba.org.uk/bsg](http://www.tamba.org.uk/bsg)  
or by sending a donation to:

**Tamba BSG  
Freepost RRAA-ASEB-AJGJ  
Twins and Multiple Births Association  
2 The Willows  
Gardner Road  
Guildford  
GU1 4PG**

Thank you.

