

# 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 

# COVID-19 UPDATE

## SUPPORT

We understand that making arrangements following the loss of your baby or babies is hard to think about, even more so during COVID-19. As guidance continues to change at a local level each hospital may have a different level of care and support it is able to provide.

If your baby or babies have died during this period some things may be a little different, but you should still receive good bereavement care. Please be assured that although there may be changes in the way care is provided, the dedicated NHS bereavement midwives will continue to do all they can to help and support you, as best they can, during this time.

You should still be offered time to spend with your baby/babies after they have died and may still be given memory making opportunities such as taking photos, taking hand and footprints, bathing and dressing your baby, creating a memory box, etc. If this is something you would like to do, check with the staff to see if this will be possible, or you may consider taking your own photos to look back on later. Many families treasure the photos they have from their time in hospital and find this an important part of remembering their babies who have died.

If your baby/babies are on a neonatal ward you should both be able to visit them. UK charity Bliss supports families whose babies are born premature or sick and has some excellent information on neonatal care during the COVID-19 pandemic on its [website](#).

Sands, the leading stillbirth and neonatal death charity in the UK, has also produced a [guide regarding COVID-19](#) and the changes that may have an impact on bereaved families.

## MIDWIFE AND MATERNITY TEAM

During the COVID-19 pandemic, it is very important that if you have any questions or concerns about yourself or your babies at any time, you contact your midwife or maternity team.

You and your partner should both be able to attend all scans and appointments so please ask at your hospital if this is not the advice you are given.

For monochorionic pregnancies, please familiarise yourself with the **signs of TTTS**.

Contact your maternity team immediately if you have any concerns regarding your babies' movements.

## NHS

The current NHS England and NHS Improvement campaign 'Help Us, Help You' is a reminder to all pregnant women about the importance of attending check-ups, contacting their midwife or maternity team when something doesn't feel right and gives reassurance that the NHS is here to see you safely.

## RCOG

The RCOG (Royal College of Obstetricians and Gynaecologists) [website](#) is a great source of information regarding pregnancy during COVID-19.

## TWINS TRUST - HERE FOR YOU

Our support at Twins Trust remains the same so please contact us with any questions that you might have or with anything we can offer support with.

Contact us at [bereavementsupport@twinstrust.org](mailto:bereavementsupport@twinstrust.org)

[www.twinstrust.org/bereavement](http://www.twinstrust.org/bereavement)



Thank you to the National Lottery Community Fund for funding additional information relating to COVID-19.

# 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. 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.

Tamba have an on-line facility to provide virtual peer to peer support. Details of this caring supportive community can be found by contacting [support-team@tamba.org.uk](mailto:support-team@tamba.org.uk)

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 Tamba Bereavement Support Team [support-team@tamba.org.uk](mailto:support-team@tamba.org.uk)  
You can also call Twinline on 0800 138 0509

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 Group (BSG) 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.**

Sharon Darke

Tamba Bereavement Support Coordinator

**77% OF FAMILIES WHO COMPLETED OUR SURVEY IN 2016 SAID THEY HAVE READ THE BOOKLET AND RATED IT 4.5 OUT OF 5. ONE PARENT SAID:**

**“ THIS BOOKLET HELPS PEOPLE UNDERSTAND THEY ARE NOT ALONE - THERE IS HELP AND SUPPORT. THINGS WILL GET EASIER ”**

## 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 babies is not unusual. Twins are 4 times more likely to die during pregnancy compared to a single baby and 7 times more likely to die shortly after birth. Please do not feel isolated in your grief. You are not alone – the Bereavement Support Group at Tamba is available to any parent who has suffered a loss through a multiple birth pregnancy or whose baby or babies have died after birth or for anyone who has lost a child or children from a set of multiples. 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 (**01252 332344**). 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 them.

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 (TTTS). 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 TTTS was not an issue. He did feel however that we would encounter a syndrome 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. 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

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

“ I FELT ROBBED OF THE ALL-CONSUMING HAPPINESS NEW MOTHERS SHOULD FEEL AND SOME DAYS WERE REALLY BLEAK ”

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

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.

I have realised as Harry has grown that my fears about him have not so far been borne out, and indeed he was a beautiful happy little boy, and now teenager! These are always there as Harry has got older and reached milestones in his life. At one time, I believed I could never go through another pregnancy and the fact that two years later 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.

I was helped enormously by speaking to a befriender in the early days, as until then, I did not feel anyone really understood. I have subsequently joined TAMBA'S BSG as a befriender myself and am happy to talk to anyone who is going through something similar.

“ I WAS HELPED ENORMOUSLY BY SPEAKING TO A BEFRIENDER IN THE EARLY DAYS, AS UNTIL THEN, I DID NOT FEEL ANYONE REALLY UNDERSTOOD ”

## 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 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.**

## 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.

## A 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' on page 12.

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 questioning your feelings of grief. The bond between expectant mother and unborn babies is real and your grief is a valid reaction.

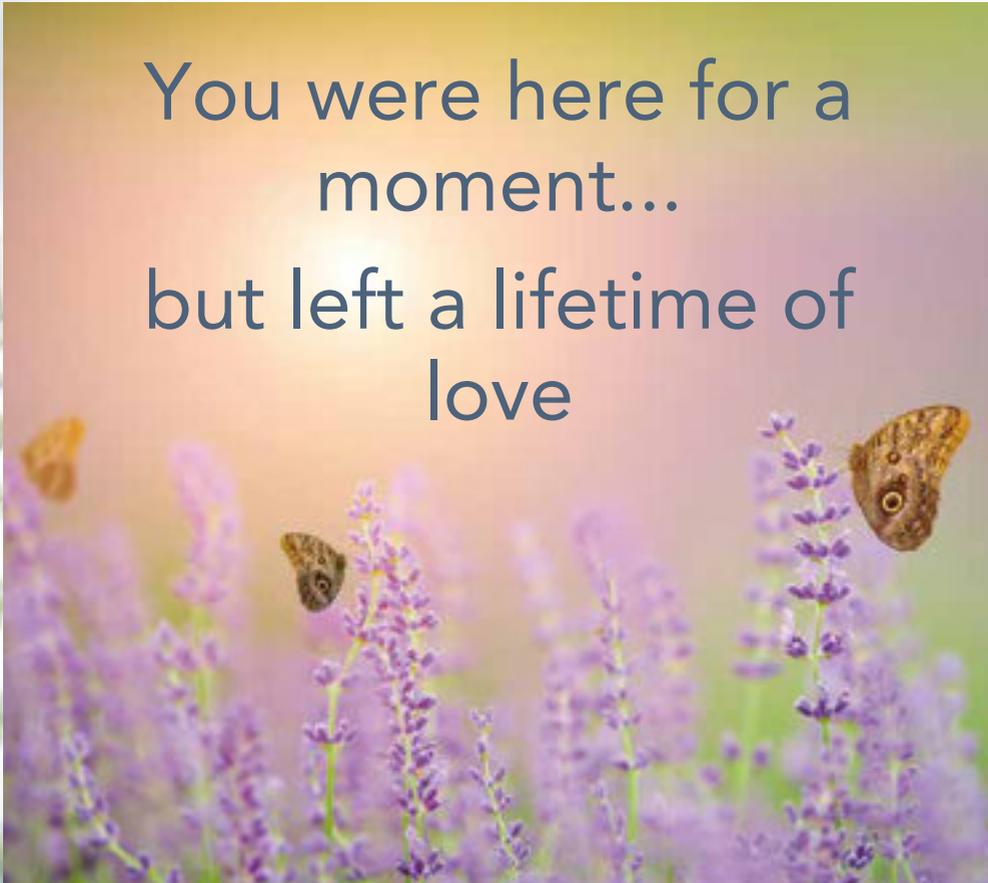
If one or both babies die after 14 weeks, you may be able to see them if you wish. If your babies have grown enough and the loss happened in hospital, you may be asked if you would like to hold them and dress them. Although it is upsetting saying goodbye

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.

You were here for a moment...  
but left a lifetime of love



## 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

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

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it out, but still no joy. They then decided I would have to go and 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.

surviving, but the doctor who saw me at 10 weeks didn't tell us this. He gave us false hope, which made things so much worse.

I gave birth to the twins on Saturday 16th December 2006, which was within a few days of the miscarriage. That was

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

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, I was 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 got 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.

## 4 LOSSES, 2 YEARS - LEARNING TO LIVE AGAIN AFTER MULTIPLE STILLBIRTHS: CLAUDIA BELARDO

"So what happened to us? Early in 2010 I fell pregnant quickly, our first pregnancy, and we were blessed, naturally, with twin boys Vincenzo and Benedetto. One business trip to Australia later and we were ready for the 12 week scan and like every first time lady I was sure, entering that scan room convinced that I was going to see nothing. The very kind sonographer gelled me up and started

were drawing a different picture, but we didn't understand this yet. In my happy little world I was convinced Little Sprout, who was consistently behind in growth compared to Wallaby, was a girl and Wallaby was a boy. It had to be ok after all Nuchal tests showed a 1 in 17,000 and a 1 in 15,000 chance of Down's syndrome.

Still they were trying to tell me something else but I couldn't hear

them and didn't want to listen. The Consultants were kind but their words were all fluffy so as not to shock I suppose, so I carried on in blissful ignorance. At the 16 week scan they told

“STILL THEY WERE TRYING TO TELL ME SOMETHING ELSE BUT I COULDN'T HEAR THEM AND DIDN'T WANT TO LISTEN”

to move the little device backwards and forwards over my tummy and after a brief pause said "So, here is one of your babies, and, and, well - here is the other one". Those were her words to us. Our mouths dropped, my husband started crying. So that very first scan revealed Little Sprout showing as 9 weeks and 6 days old and Wallaby showing as 10 weeks and 2 days old.

So the pregnancy progressed, health-wise I suffered from all-day nausea until week 12 but aside from that was healthy despite my vastly advancing belly. The scans however

us they needed to refer us to more consultants at Oxford. I know now that the signs being indicated at the scans were not at all good but not even the doctors knew why.

Oxford gave us plain, straight talking. They told us that Little Sprout was unlikely to make it, that they couldn't tell what sex he was because he had remained in the same energy conserving fetal position for many weeks and was making little movement. The consultants, all three of them, told us that the 'prognosis' for this pregnancy was that we would come out

of it with one healthy child - the boy, Wallaby (who we would later christen Vincenzo). Little Sprout wasn't growing, his Dopplers were reversed, there could be a congenital problem but it wasn't his heart as far as they could tell. They couldn't tell us anything really except that there was nothing to be done and that he would probably die in the next couple of weeks.

Three weeks later however Little Sprout was still hanging on. Wallaby was also doing fine, being scanned at the fetal medicine clinic on a weekly basis. My blood pressure started rising, and so suspected pre-eclampsia enters into this story and I was put on bedrest.

At week 23 Wallaby's growth had also slowed, a Doppler for one of the cords was showing absent flow. The consultant told us not to worry, that we needed to go to Oxford again to the Silver Star team to discuss early delivery.

Week 24+2 - New Year's Eve,

would result in no babies. Wallaby's absent Doppler meant he was unlikely to grow to a viable weight (viable means over 500g) and was estimated at 395g. Little Sprout was still 'alive' so far as to say he had a beating heart but was severely compromised from the restricted growth. His heart was beating but he was probably brain damaged, his estimated weight was a tiny 145g.

Our choices that day were:

- 1- Do nothing and let nature take its course.
- 2 - End the pregnancy completely.
- 3 - Opt for selective feticide on Little Sprout in the hope that it would keep the pre-eclampsia at bay and 'buy time' for Wallaby to put on enough weight to become viable.

At 4pm on New Year's Eve 2010 we made the decision to try to save

“ I FELT UTTER GRIEF FOR WHAT I CHOSE FOR LITTLE SPROUT AND MY HEARTBREAK AT THE DECISION THAT I HAD MADE, WHETHER IT WAS GOOD OR BAD ”

Oxford Fetal Medicine clinic. A total of five consultants were involved that day in what was described as a 'very rare and unusual situation'. The diagnosis was Severe Intrauterine Growth Restriction (IUGR). We were presented with three options and the worst prognosis was the pregnancy

Wallaby, considering the suffering that Little Sprout was going through and after many tears decided on Option 3. I won't go into detail about this procedure but up until then it was the hardest and most distressing thing I had ever had to go through, I even asked my husband to wait outside

so he didn't have to watch. It was supposed to get better, but it got worse, I felt utter grief for what I chose for Little Sprout and my heartbreak at the decision that I had made, whether it was good or bad - I was still guilty.

“ I ALSO ACTIVELY VOLUNTEER AS A BEFRIENDER FOR TAMBA BSG ”

A week later I was visiting the fetal medicine clinic on a daily basis for scans. I spoke to Wallaby daily, willing him along, even my husband started touching and talking to the bump again, something that he had stopped doing for weeks when the uncertainty became apparent. On the Monday all was looking good and I felt him move. Tuesday I had a temperature but put it down to my sore throat which my husband and I had picked up. Wednesday's scan still showed Wallaby's heart beating away, and I still felt him moving which was unusual.

But on Thursday 6th January 2011, there was no heartbeat. I had lost them both. They were stillborn Friday 7th January 2011 at 25+2 two tiny, beautiful sons ; Vincenzo (Wallaby) was born weighing 280g and Little Sprout, who was another little boy, we named Benedetto. He weighed 140g.

Then after those funerals we decided to try again, to ease the pain of our sons being taken away and I fell pregnant with our third baby and promised

rainbow, another son. Tragically Gabriele also succumbed and was stillborn 9th October 2011 at 28 weeks. Then when our fourth son Santino was also stillborn on the 21st November 2012 at 26 weeks it never occurred to me to react in any other way.

I knew what the postmortem reports were detailing. They were seeing a rare recurrent placenta condition called Chronic Histocytic Intervillositis, again not terribly well researched but with recurrent rates that made for poor reading. So I researched it and how the immune system worked. I networked with other mothers who were diagnosed with the same, I authored papers that others can now take and present to their consultants when deciding next steps.

For us I also didn't want to give up but decided that another pregnancy was off the cards. At that moment, if I hadn't started researching surrogacy, I probably would never have met the lady which would then go on to carry our three year olds now. This opened a whole new avenue listening to other couples also looking into surrogacy and not knowing where to start.

So now, as well as raising our twin boys and working full time, I also actively volunteer as a befriender for TAMBA BSG, talk on midwifery training days about surrogacy and bereavement. I also allow my story to be used in case studies and try to encourage anyone that will listen about how the role of the mother's immune system needs to receive closer research.

## 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 them 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.
- Take hand and foot prints of your baby/babies.
- 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.



## MY STORY OF SELECTIVE FETICIDE IN MONOCHORIONIC MONOAMNIOTIC (MCMA) TWINS: SALLY FOX

On the last day of the school summer term 2015 I found out that I was pregnant. I had not felt well for a number of weeks and finally went to the nurse at work who suggested a pregnancy test, which, after the longest 10 seconds of my life was positive! I was terrified and sat in her office for 10 mins shaking, she was very supportive and made me feel reassured. I then went to break the news to my husband. We

we had the opportunity to have a family. We went into the waiting room at the hospital and I was shaking, the sonographer was lovely and said 'I can see a heartbeat' very quickly which was very reassuring. Then she smiled and said 'oh, and another one' at which point I burst into tears. She explained there were two heartbeats and they were wriggling around a lot so when we tried to see them on the scan it could

have seemed that there was just one baby from different angles. They seemed to swap taking it in turns to be in front of the scanner! As we left the sonographer passed me my notes which said 'MCMA twin pregnancy'. At that point I was around 11 + 3 so we had to come back the following week for a follow up scan at

12 +3 to be able to do the full checks which are carried out at a normal 12 week scan. My husband asked what 'MCMA' meant and the sonographer smiled and said 'it means we will see you a lot, do not worry'. We left the scan feeling very happy, but I was still terrified about the prospect of twins. Turns out there is a lot to worry about with MCMA pregnancies.

Twins run in my family, I was a twin and they died in utero early on in

my mum's pregnancy. My mum is a Dichorionic diamniotic (DCDA) twin, as is my grandmother who had a twin sister who sadly died three weeks after being born. I spoke to my mum about the twins and she put my mind at rest as much as possible and life carried on. At the following scan I was seen by a different sonographer who could not get a clear view so moved me to another scanning machine, this made me even more anxious. We got into the room and he called in a colleague, then another one and then there were three sonographers staring at the screen trying to work out what they were seeing. Finally, after what seemed like an eternity, I asked 'what on earth is wrong?' and the third sonographer said, one of the babies has spina bifida. Then they called the fetal medicine midwife, our hopes and dream were shattered. The midwife was fantastic, she took us into what I call the 'dead baby room' (with no windows) and told us that there was a very good chance that one of our twins had spina bifida. She explained our options in relation to the spina bifida and then laid out the worst news of all, because our babies were MCMA's they shared the same placenta and the same amniotic fluid. This meant that the poorly baby was inextricably linked to the healthy baby and anything we did would pose a considerable risk to the healthy baby. This meant that we were presented with two options - terminate the pregnancy now or go for a referral to look into the possibility of a selective feticide of the unhealthy baby. The words make me shiver just hearing them, it sounded

horrendous. The midwife explained that the doctors would terminate the unhealthy baby with an injection directly into his heart. This was just too much to take and I fell apart in the tiny horrible room with no windows. I think there is a reason it has no windows, so no one can see the breakdowns so many other parents must have in there. My husband was so strong and held it together to ask the important questions and hug me. There was no other option, have a termination of both babies or have one terminated due the huge risk he posed to his brother.

So, off we went to University College Hospital. We were seeing their top twins consultant. He was brilliant, a lovely warm reassuring man who explained there was a new procedure which could be undertaken to try and save the healthy twin. He had so much time for us which made me feel so much better, he never hurried us or got bored of our hundreds of questions. He confirmed the twins were definitely MCMA's and that one of the twins had OEIS complex (this is a complex combination of many life threatening problems). The consultant explained there was a good chance (more than 90%) that the healthy baby could survive the procedure. The consultant would ablate the cord and cut of the blood supply to the poorly baby resulting in the demise of the poorly twin. After lengthy discussions with the consultant we were given the afternoon to consider which course of action we would like to take. We felt positive about the possibility of maybe one of our babies surviving as we did

“ WE WERE PRESENTED WITH TWO OPTIONS, TERMINATE THE PREGNANCY NOW OR GO FOR A REFERRAL TO LOOK INTO THE POSSIBILITY OF A SELECTIVE FETICIDE OF THE UNHEALTHY BABY ”

were both in shock as we had never anticipated that I would get pregnant so quickly, we had not even really discussed it actually happening as we presumed there would be plenty of time waiting before being so lucky in our first month of trying. I did all the usual things next and then got my appointment at the hospital for my 12 week scan around a month later. I was nervous and excited about the prospect of having a baby and delighted that

not have much hope from our local hospital that there was any positive outcome for either of the babies. As we returned to see the consultant we had made the decision to go ahead with the procedure and try and save one of our babies. This was the worst decision of our lives, we had to agree to kill one of our babies in order to try to save the other one. The other options which were presented to us was to leave the babies and let nature take its course. We were advised strongly that what would most likely happen in that circumstance would be that the poorly baby would die and then kill the healthy baby well before I got to term. We considered this choice and decided that with a 90% estimated chance of survival, it was the best option in light of the risks of doing nothing. The final suggestion was that we terminate the pregnancy - this was not something which we considered. We were provided with a date for the procedure in 3 weeks time. This was the wait of a lifetime. I was constantly thinking the poorly baby had died and therefore so had the healthy one so I envisioned sitting on the bed in the consultation room and the doctor saying 'I'm sorry your babies have died'. I felt guilty everyday for the decision we had made, but there seemed no other choice. We had to wait three weeks to give the surgeons the best possible chance of the procedure being successful and that meant allowing the babies the opportunity to grow. This in itself seemed cruel - allow our baby to grow to give the surgeon a better chance

of killing him successfully?

We were in the most horrific situation and there was no good way out. Three weeks passed and we went to London prepared for the procedure. We went into the consultation room and had a scan to see if the babies were alive and then to see if they had grown sufficiently to enable the procedure to go ahead. A second consultant was now involved and I spent around forty minutes being scanned by both consultants with them discussing how they would perform the procedure. The words 'you are between a rock and hard place' came from the second consultant's mouth. This was not what we needed. Every time anyone had looked at my uterus they had bad news. The poorly baby had a further problem - its bladder was protruding because it could not be emptied. This meant that the space which was available for the surgeons to carry out the procedure was reduced and therefore they decided to leave me for another week. The idea was to increase the amount of amniotic fluid in my uterus and therefore increase the space they would have. The following week we went and the procedure was performed. The consultants were not happy with the amount of fluid but felt risking the boys one more week would not be sensible. It was like I was a walking time bomb. Each and every time we went the boys were both alive and kicking, you could see them swimming around each other and it seemed like they were having a nice little time. I know that is such an odd thing to say, but it is how they looked.

My husband watched each scan and said they just looked like normal perfect babies bouncing around on the screen having fun together. Again, another scan and another bit of bad news. As they were MCMA's their chords were tangled (apparently this is normal as it would be impossible for this not to happen) they looked like a ball of knitting. The consultant made me look at this so he could explain how much more difficult the procedure had become. I didn't want to look as I didn't want to believe there could be any more bad news.

The boys had done so well just staying alive and fighting to keep going, why did more things have to go wrong? At this point the consultants explained they no longer had any statistics to give us as the procedure had become so much more complicated. The procedure lasted nearly two hours. Once it was over the consultant said 'it went as well as we could have hoped' which is never a good thing! It should have been 15-20 mins. I was awake the whole time laying there with my husband, I tried not to concentrate on what was happening as I don't think I would have stayed still. We returned to UCLH the following morning to find that both babies had died. The most likely reason for this, we were told, was that because the boy's were sharing literally everything, it meant that as one of the boys blood pressure dropped during the procedure and his brother tried to rebalance the blood pressure and died in the process. Nearly a week later I went into our

local hospital to deliver the boys. This was the most emotionally horrendous part - but in some ways the easiest part, I really had nothing to lose. The pain was nothing in comparison to the pain of knowing the boys had died. I almost did not want to give birth, as I knew the boys would be gone forever and would never be able to be close to them again. The fetal medicine midwife came to see us again and asked if we would like to see the boys, this was something that we were unsure about and she said 'they just look like really tiny pink babies' so we did. I am glad we did see them. We cuddled them and said 'see you later' to the boys rather than 'goodbye' as that seemed to be less final. Now, 10 months later, I have since had a miscarriage at seven weeks and feel that the whole experience of being pregnant and trying for a baby has been one disaster to the next. Despite what has happened to our family, we will continue to try and hope that one day our boys will have some siblings that share their life on earth with us. The support we have had from TAMBA has been amazing and one of the things my befriender said to me was 'you have been through the worst, you are still here, so you can get through anything' this is something which I tell myself every time something bad happens and it helps me get through this ongoing nightmare. I am happy to talk to anyone going through something similar. We have now had our rainbow baby, a beautiful, healthy little boy.

## TRIPLETS WITH TTTS SHELLEY AND PAUL HARROD

This time last year our world fell apart. It was the start of an 8 day stay in Queen Charlottes and Chelsea Hospital. From the start of our pregnancy we were extremely high risk as all 3 babies were sharing 1 placenta which meant that we were monitored weekly. It also meant that all 3 babies were extremely hard to monitor as essentially they were on top of each other. Every week was a hurdle and blessing in itself to get through. Most appointments showed some

TTTS developing to the next stage, our consultant made the decision to rush Shelley to Kings College Hospital, where Professor Nicolaides would carry out laser ablation, finding every blood vessel connecting the triplets and closing them to prevent the flow of blood from one baby to the other and the possible risk of transfusion and an amnio reduction, draining excess amniotic fluid from around the larger recipient triplet.

This surgery went as well as the Professor imagined and the placenta was divided into 2. It was then a waiting game. How long could the babies stay inside for? This surgery came with an extremely high risk of premature labour.

Spending the night

“ LESS THAN A WEEK LATER AT THE 22 WEEK SCAN, SHELLEY WAS SHOWING EARLY SIGNS OF TWIN TO TWIN TRANSFUSION SYNDROME TTTS ”

cause for concern with 1 of the babies and it was only at 21 weeks that we had our most positive scan, where no concerns were raised.

Less than a week later at the 22 week scan, Shelley was showing early signs of Twin to Twin Transfusion Syndrome (TTTS). Within 3 days the symptoms completely spiraled out of control which led to spending the following 8 days in hospital. At the time we hoped it would be at least an 8 week stay and we would be bringing home 3 healthy babies.

After a 1 night stay in hospital and

in Kings College Hospital delivery suite, not knowing any of the staff there and worrying what would happen during the night, our thoughts we will never forget. The consultants and doctors could not believe that the babies had made it through the night. This was a huge milestone. Shelley was then discharged by ambulance back to Queen Charlottes and Chelsea Hospital where constant monitoring continued.

The following day the consultant scanned and confirmed that the baby

in the middle had no heartbeat. We broke down in tears. Now we had to stay strong for the other 2 knowing that Shelley would be carrying that baby still. The hardest days were yet to come.

On the 26th February 2015, Shelley went into premature labour after a long 48 hours. Each of our baby girls were delivered, perfectly formed, so beautiful and sleeping peacefully. We could never have been prepared for the worst even though the neonatal team had talked to us but they were just too small at 23+3 weeks gestation to survive.

We will be forever grateful for the

compassion and care from all staff at both the hospitals for doing everything they could for us and our precious girls. For the rest of our lives they will always be a huge part of our family and everything we do.

Upon coming home from hospital, we were in touch with TAMBA Bereavement Support Group who sent us lots of information in the post and we have been part of a bigger network of grieving parents of twins and triplets. We really would not have got through this past year without this support and befriending offered to us. No one wishes they were a part of this group.

## MY TRIPLET PREGNANCY TRACEY KIRBY

I found out I was pregnant with triplets last March at 13 weeks with a singleton and identical twins. We went for scans every week at the UCLH. At 19 weeks we discovered that our ID twins had TTTS and were advised to have a selective reduction as we could not have laser surgery as the placenta was in the wrong place. We decided to let nature decide and hoped that the TTTS would stabilise, which it did for a few weeks until 23 weeks when it had got a lot worse. I was advised to selectively terminate our little one of the ID twins as they thought the TTTS had gone too far. We decided to go for laser treatment as the placenta was now in the right place. All was well for

a couple of weeks but at our 25 week scan we found out that our bigger ID twin had passed away the day before on 17th June 2015. We were told to expect the same to happen to our other ID twin but at 32 weeks my waters broke and with a c-section had my 3 lovely boys, my 2 survivors, James our singleton weighing 3lb6oz and Henry our twin 3 weighing 1lb8oz. Our third little man who passed away, we decided to call Cayden. James was in hospital for 3 weeks and Henry for 6 weeks. Luckily James only needed CPAP for breathing for 3 hours and Henry didn't need any help. They are now 10 months old and although they are small they are doing well.

## LOSS IN INFANCY

If your babies were born alive, but died in the first few months of life, it is likely 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

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

“ THANK YOU TAMBA FOR PUTTING ME IN TOUCH WITH MY BEFRIENDER. SHE IS LOVELY AND SO SUPPORTIVE. I JUST FEEL I CAN BE MYSELF, EVEN THOUGH I’VE NOT MET HER, I KNOW SHE KNOWS HOW I FEEL AND I KNOW WHAT SHE SAYS COMES FROM THE HEART ”

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

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 rollercoaster 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

“ 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 ”

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.

### SUDDEN INFANT 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 Lullaby Trust for the Study of Infant Deaths (FSID) has a helpful booklet 'When a baby dies suddenly and unexpectedly'. They have a Helpline 0800 8026868 and support@lullabytrust.org.uk

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 Sudden Infant Death (SIDS), 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 SIDS – 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.

The Lullaby Trust 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 The Lullaby Trust helpline.

# 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.

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, 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. Here is the link: [www.gov.uk/funeral-payments/eligibility](http://www.gov.uk/funeral-payments/eligibility)

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. 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 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: [www.climb-support.org/](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,

## 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?

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.

## LISA OSBORNE ASKED FOR DONATIONS AT PHOEBE'S FUNERAL

"My identical twin baby girls were born unexpectedly on 1/12/15 at 30 weeks gestation. Phoebe was unfortunately born sleeping and Chloe fought on in neonatal but has severe brain damage. We still do not know the reason why Phoebe was not alive when I went into hospital for a planned scan but the evidence after their birth showed some kind of acute twin to twin transfusion had occurred, we don't know why or when. I wanted to raise money for Tamba's Big Research Appeal by asking friends and family to donate at Phoebe's funeral."

## 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 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

After an extremely difficult and complicated pregnancy our gorgeous twin boys were born via C-section on the 27th April 2009. Oliver weighed 1400grams and Joseph a mere 635! They were rushed to intensive care. 6 days later we lost Joseph to NEC (Necrotizing enterocolitis). At this point Oliver was doing really well, but 2 weeks later he also contracted NEC and we lost our second boy to

was as if we had hit a fork in the road on our 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 days on end crying at home and looking at photos. 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

“ FROM THAT POINT ON, MY WIFE AND I REALLY STRUGGLED WITH OUR EXTREMELY INCOMPATIBLE JOURNEYS ”

the same disease. We still cannot describe the desperate feeling of loss we both have in our hearts. From that point on, my wife and I really struggled with our extremely incompatible journeys.

All my wife wanted to do was cry and talk, but I wasn't ready to talk, all I wanted to do was get back to work and keep busy. The biggest thing we have since learnt from our experience is that grief is an extremely unique and personal thing. Understanding this at the time was impossible though. Neither of us could see it. Looking back on things now, it

too, but at the time she couldn't see that. It was as if she thought I didn't care and that I just wanted to get back to normal? 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 was scared of what might happen if I stopped.

My first day back in the office was extremely difficult. I remember arriving in the carpark, sitting in my car for a good 15 minutes before I gained enough courage to enter the building. Walking through those

“ I NOW KNOW HOW IMPORTANT IT IS TO UNDERSTAND THAT WE ALL GRIEVE IN EXTREMELY DIFFERENT WAYS, WHAT MAY BE HELPFUL TO ONE PERSON IS NOT ALWAYS RIGHT FOR ANOTHER ”

doors that day 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. I went straight to my office and tried to make myself look busy, but I just could not concentrate, my mind kept wandering, thinking about our boys, how my wife was coping for the first day on her own, and our failing relationship. I wanted to go and get a coffee, but wasn't ready to be around people chatting about their wonderful weekends, 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 welcomed me back to work. What shocked me the most was 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. Personally I

didn't find these groups that helpful, although I could see they were really helping my wife, so I continued to support her by going along to them with her. Finally we found the Child Bereavement Charity which just seemed to click for us both.

I now know how important it is to understand that we all grieve in extremely different ways, what may be helpful to one person is not always right for 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.

Eventually our paths finally re-joined, we learned to deal with our loss as a couple and managed to move forward with our lives. Eight years on we are a much happier and stronger couple and have since had two beautiful girls, Ellena who is nearly 6 and Georgina 3. Our beautiful boys will never be forgotten and we talk about them every day, they are still a major part of our family and always will be...

## LOSING ONE OF OUR TWINS: JOHN GARDEN

In January 2014, we went into hospital expecting to give birth to our boy/ girl twins. The pregnancy had been exceptionally healthy and there were no known issues with the babies. During labour, our daughter fell on her own umbilical cord and died. Our twins were delivered just after midnight. Our daughter was stillborn. Our son was perfectly healthy. We believe that our daughter would also have been perfectly healthy, had it not been for the terrible accident she suffered in the hours before her birth.

The night of the birth was traumatic, devastating, joyful, wonderful, and everything else in between. I still cannot properly describe the mess of emotions we went through that night.

We were very lucky to be surrounded by an amazing team at Gloucester Royal Hospital. I will never forget the level of care and understanding that we received there. After 48 hours, we moved to a smaller maternity unit, and a day or so later, we went home. Leaving the hospital with one child is usually the best feeling in the world for most parents; for us, it was the most bewildering mixture of the deep love we immediately felt for our new son, combined with an almost unbearable pain, impossible to comprehend.

I can now safely say that through

most of the first year after the birth, we were in a state of shock. I am forever grateful to the support and counselling we received from our GP, our bereavement midwife, Footsteps in Gloucester, TAMBA, and Child Bereavement UK. We were also (obviously) supported by our wonderful families and friends, and continue to be.

Returning to work, for me, was unknown territory. I learnt a lot about myself, my limits for suffering, and about the importance of working with people that care about your emotional welfare. Two months after the twins were born, I went back to work as musical director for a short tour of the UK. The management, touring crew, and my bandmates were so understanding and supportive - it felt like coming home to family.

It is now two and a half years later and we are stronger and more at peace.

I read once that love is knowing the beginnings of grief. I didn't really understand that before but I think now I do.

If you are a bereaved parent reading this, please know that my heart goes out to you. Maybe time does heal, maybe it doesn't, but at the very least, time will give you more breathing space between the moments of grieving. I hope you find more peace and less pain.

## BECOMING A BEFRIENDER FOR TAMBA: RICHARD BOYD

Befriending seemed the next natural step after confronting years of delayed grief for my twin sons.

In those early brutal days of loss the TAMBA Bereavement Support Group became my online second home.

In the non-days that came when I returned (physically, if not mentally) to work the group was my safe haven, a chance to speak to people that understood what is like to lose your babies.

them but also to encourage other fathers to talk about their experiences.

Befriending allows me the chance to do that directly. It doesn't have to be a phone call, it can be by email. It's whatever is best for the person that needs that help.

Befriending is not about giving advice. It's not counselling but is a chance to be heard without judgement or fear.

Sometimes just having someone to listen to you speak out the words that have been swirling round your head allows you that chance to hear yourself.

It can be for one call, one email or a longer term basis. Grief is marked by its ebb and flow and even years afterwards it can hit with the force of those raw early days.

Befriending is for all those times when you need

someone to hear you say the things you may not feel you can say to those closest to you.

There is no right way to grieve but I know from experience that some ways may be better than others. Putting on a brave face, feeling the need to be strong can be exhausting and damaging and unintentionally isolate us from the ones that need us most.

If you or your partner need space to talk then please contact the befriending service. We are here to help you as others have helped us.

“ BEFRIENDING IS NOT ABOUT GIVING ADVICE. IT'S NOT COUNSELLING BUT IS A CHANCE TO BE HEARD WITHOUT JUDGEMENT OR FEAR ”

It's a place where we can be open about all the ugly feelings of guilt, rage and despair and help others through their darkest moments.

It's also a place where we can talk about the mixed feelings of pregnancy after loss.

The need to talk can be overwhelming and not having someone to talk to can be isolating and intensify an already unbearable pain.

I started writing to get those feelings on page to make sense of

## 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 to think 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.

Kate Polley, who also lost a twin and wanted to help her surviving twin and her other children to understand that we can experience the love and joy of a loved one, even when they are no longer with us here on earth, can produce personalised books, 'The Story Of...' books for families who have lost one or both twins.

[www.personalisedchildlossbook.com/sam-and-finn/](http://www.personalisedchildlossbook.com/sam-and-finn/)

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

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

### JEANNE REILLY

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, 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.

babies in mummy's tummy, have 'died' – children often welcome having a new word to understand an event 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 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 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

## A TWINS PERSPECTIVE CHRISTINE SPOORS

I don't remember a specific moment in my life when I realised that Elizabeth wasn't alive. For as long as I can remember I have known I should have an identical twin. I've always known that she didn't survive the complications that occurred when we were born. I am glad that my Mum and Dad told me about her from a young age. This meant by the time I was old enough to understand death I had already accepted what happened. I think it would have been difficult to process if they waited until I was a teenager to tell me.

Mum tells me there were a few times in my childhood where I was emotional about it, but I honestly can't remember them. I think if my parents had never told me about it I would have been annoyed with them when I found out. I am still a twin and I like to know that. Oddly, it makes me feel special.

Sometimes when I see twins I wonder what it's like to have someone you've grown up with since birth, or when I look in the mirror I think about how strange it would be to see another human being that looks exactly like me. At times, I find myself thinking the most ridiculous things; I am quite short so I wonder if one of us would have been taller than the other.

I am lucky I am really close with my younger sister, we never fight and it's like having a best friend who lives with you. I think because we are so close it means there isn't a gap in my life. I'm not on my own and as it's only the two of us, we always had someone to play with when we were younger. I can't say if having a sister has made it easier to deal with or not because I can't imagine life without her.

I am quite a positive person which perhaps helps me deal with it. When I think about it I feel more upset for my parents. They are the ones who met her and had to deal with her dying. Luckily I was far too young to remember it. It's like if someone told you a relative died before you were born, you would find it difficult to spend too much time being sad about them because you never knew them. I think knowing from a young age makes all the difference. I was so curious about what happened and I think knowing the truth about it stops it from being a mysterious and horrible thing. Of course, I wish that she would have survived, but I don't think that any good would ever come of me dwelling on it and repeatedly making myself upset about it. I still have the rest of my family and one amazing little sister.

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.

## 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 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.

## 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.**

# JACOB (2/10/11) AND GEORGE (6/10/11) – GRANNY'S STORY

## SUE BAMBLETT

When I heard Sam was expecting twins, I was over the moon. I shared in the joy and excitement as Sam and Jim prepared for the birth; I shared the worry when things started to go wrong; and finally the heartbreak, loss and devastation when things got worse. It was such a privilege to meet those two little soldiers. They battled so hard to live. I wish I could fix things. I wish I could take the pain away, put things right - I'd gladly have given up my life that they might live. I won't ever forget you - you'll always be with me, part of our family. I am so glad I had the chance to hold you and tell you how much I love you.

### Sunday 18th September 2011

At 11.00 am Sam's waters break. We take her to Kent and Sussex Hospital Emergency - she's quickly transferred by ambulance to Pembury. We're told that if the babies come today, they are not viable - they won't intervene. Thankfully everything calms down.

### Sunday 25th September

Sam is having contractions. Sam is examined - 3cm dilated. Contractions are fast and furious. They tell us the babies are not viable if they come today - under 24 weeks and under 500g. In despair I pray to God to save these little boys. I reason with the doctors - persisting on their behalf - fighting their corner. One lady obstetrician is on our side. She does another scan and estimates they are 495g. So close. Eventually they agree to the neonatal team attending the birth and give Sam steroids. Our euphoria is short-lived.

They send more specialists - six medics this time, lined up in Sam's room. Our pleading begins again - 'at 23 weeks they're so close - nothing to lose by giving them a chance...' Eventually they agree. Then things calmed down - Sam's contractions lessen.

### Sunday 2nd October

At 9.00 a.m. Sam is in the bathroom when Jim and I hear her scream. We rush in to find her cradling Jacob between her legs. Nothing is ready for the little mite, but he's alive! Sam is rushed to delivery with Jim. 'Stay with him,' she says to me. The doctor with me is near tears when he explains Jacob's veins are too small for intervention. I hold Jacob in my arms, telling him over and over: 'There, there, Granny's got you.' He's like a little bird. His face crinkles as I speak - a tiny flicker of movement. 'There,' I say to the doctor. 'Did you see him move?' 'It's just reflex,' he says gently, but I don't believe him.

I watch your little face - eyes tightly closed. There it is again - a flutter of life - an angel tickling your nose. When the doctor goes out of the room, I bend over your face - perhaps my gentle breath can fill your lungs with oxygen? I rock you gently in my arms, and tell you how much we all love you. The doctor comes back with a crib on wheels: 'We need to get him to his mum,' he says. I look at the crib - sterile and cold. 'Can't I carry him?' I ask. The doctor considers for a moment, then nods. When we get to the delivery room, I smile as I hand him over to his Mummy and Daddy. Jacob is declared dead 45 mins later.

### Thursday 6th October

At 1.00 am the waters around George break. They monitor Sam and George closely. His heartbeat is strong and he's a good size, but the risk of infection to Sam has increased - she's had the shakes and a temperature. At 8.00 a.m. they give her an internal examination and they give her drugs to induce the birth. They recommend a natural delivery as a c-section for Sam is much more risky this early in a pregnancy. Later I wish I had argued this, but I was so fearful of losing Sam too. The labour is difficult. George doesn't take a breath. Sam is in terrible pain - the midwife pulled the cord off the placenta so, after everything else, she has to go into the theatre to have it removed by epidural. As they take Sam away and Jim goes with her, she looks anxiously back at me. I say, 'I'll stay here.' I cradle George in my arms - he looks just like my Dad - arms folded and slightly irritated as if someone has disturbed him while he was sleeping. He's bigger than his brother - 617g. He'd have stood a good chance if delivered by c-section. Poor little soldier - you've been through such a battle.' I wrap you back up and cuddle you, telling you how much we all love you.

Just before Sam went into labour with George, she'd said: 'I'm frightened it will happen again.' 'No,' I'd said, 'this is different. George is 24 weeks and bigger. Everything will be okay.' It did not enter my head for a moment that George wouldn't take a breath. I feel I've let my daughter down. Over the next few days we spend time with the boys. They're dressed in tiny knitted clothes and we fill the Moses basket with teddies and pictures of the family. We give them lots of cuddles and take photos. On the afternoon of the 8th Sam is discharged.

She leaves the hospital in a taxi, carrying two cardboard memory boxes, instead of two babies in car seats.

### Afterwards

I used to say 'thank you' as I went to sleep - for my children and their families; for my friends; for protecting us all. Now I know there's no-one listening - everything has gone so wrong. My beautiful little girl is in so much pain and we have lost both Jacob and George. Seeing your daughter in such pain and knowing that you can't fix it, makes your own pain seem doubled. Sam can hardly bear to go on without her boys. In the hospital I had watched mesmerised, as my son-in-law Jim, gently unwrapped his dead sons, examining every millimetre of their bodies, marvelling at their tiny fingers and toes. How could this have happened to us?

### 16th February 2012

My daughter is pregnant again: 'You must be over the moon,' people say. I am just quietly optimistic. Just four months ago we lost our precious Jacob and George and no one can explain why. Twin pregnancies are complicated - I didn't understand that before. It is early days, but we are daring to hope again.

### 6th February 2017

Although I miss my grandsons every day, I carry them in my heart and I will never forget them.

Life is good - I am Granny to Sam's two darling daughters. Izzy is four and a half and Poppy will be three this month. They are beautiful, cheeky and full of life. Each year they sing happy birthday to their brothers and blow out the candles on their cakes. Izzy says to me 'Jacob and George are stars in the sky. I wish they would come down and play.'

# HELPING A BEREAVED PARENT

## SOME IDEAS OF WHAT TO DO

- Say their babies name and include them in conversation
- Approach the bereaved parent rather than waiting for them to come to you.
- Make eye contact, gently touch them or offer a hug if it seems appropriate.
- Just listen to them and allow them to cry. This is their time to talk and yours to listen
- But also ... let them be silent. They don't always need to talk.
- Don't make comparisons with your own experiences of bereavement.
- 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.
- If they say they are ok – are they really ok?
- Send a message/card 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 round. But also be aware they may want different things.
- Invite them out for a coffee, but understand if they feel they can't yet be around lots of other people.
- Understand their appearance of doing well may be deceptive.
- Arrange a specific date to meet up, rather than vague comments that 'we should get together'.
- Think about your responses – "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.
- Don't rush their grief – it can take years to accept the loss of a child.
- Don't assume that they can have more children, this may not be possible
- Remember that it is going to take a long time for them to accept what has happened. They may well not go back to being that same person that they once were. Many people say that it is a new kind of normal.

Adapted from: Hurcombe (2004); and Multiple Births: Bereavement Support website, Canada and with parents from our online Bereavement Support Group (2017)



"I wanted to take the time to thank you. I was very moved by talking to you. It was the first time in over 6 months since we lost our baby that someone got me and truly empathised with regard to the pain of losing a twin and I could really relate to many of the things you shared, it really did bring me great comfort to talk to you and I am fortunate that TAMBA and you run this service and you are willing to give so much to help others. You are doing amazing work, thank you for throwing me this lifeline"

From a Mum supported by  
Sharon and our befriending service

# 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 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.

# 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.
- Create a framed tapestry with their name, date of birth and death on.

# REMEMBER MY BABY

“Remember My Baby provides Baby Remembrance Photography to parents facing the loss of their baby before, during, or shortly after birth.



We are a registered charity and our service is entirely free of charge.

When a couple are given the devastating news that their pregnancy is ending in the most unexpected way, the last thing on their mind is professional portraiture. That's where we come in. Remember My Baby has a growing network of professional photographers throughout the UK, who are willing to use their skills and give up their time to capture a lasting and tangible memory of their baby, at no cost to the parents or to the hospital.

Launched in August 2014, our goal is for every maternity unit and birth centre to have at least one Remembrance Photographer attached to it.

There is a very limited window of opportunity to capture images, and we are accustomed to attending hospitals at very short notice, usually the same day we are called upon. However, we have met families a few weeks after their baby has passed away, sometimes in a funeral home, and still been able to capture images for them to remember their baby by. We also visit NICU and Hospice where baby is nearing the end of their life. Each family receives black and white images on a special Remember My Baby USB memory stick, from which they can have prints made at an outlet of their choice.

For parents who were unaware of Remember My Baby's Remembrance Photography service, we offer a Retouching service, also free of charge. Parents can submit 4-6 images to our team of Digital Retouchers who will do their best to assist.”

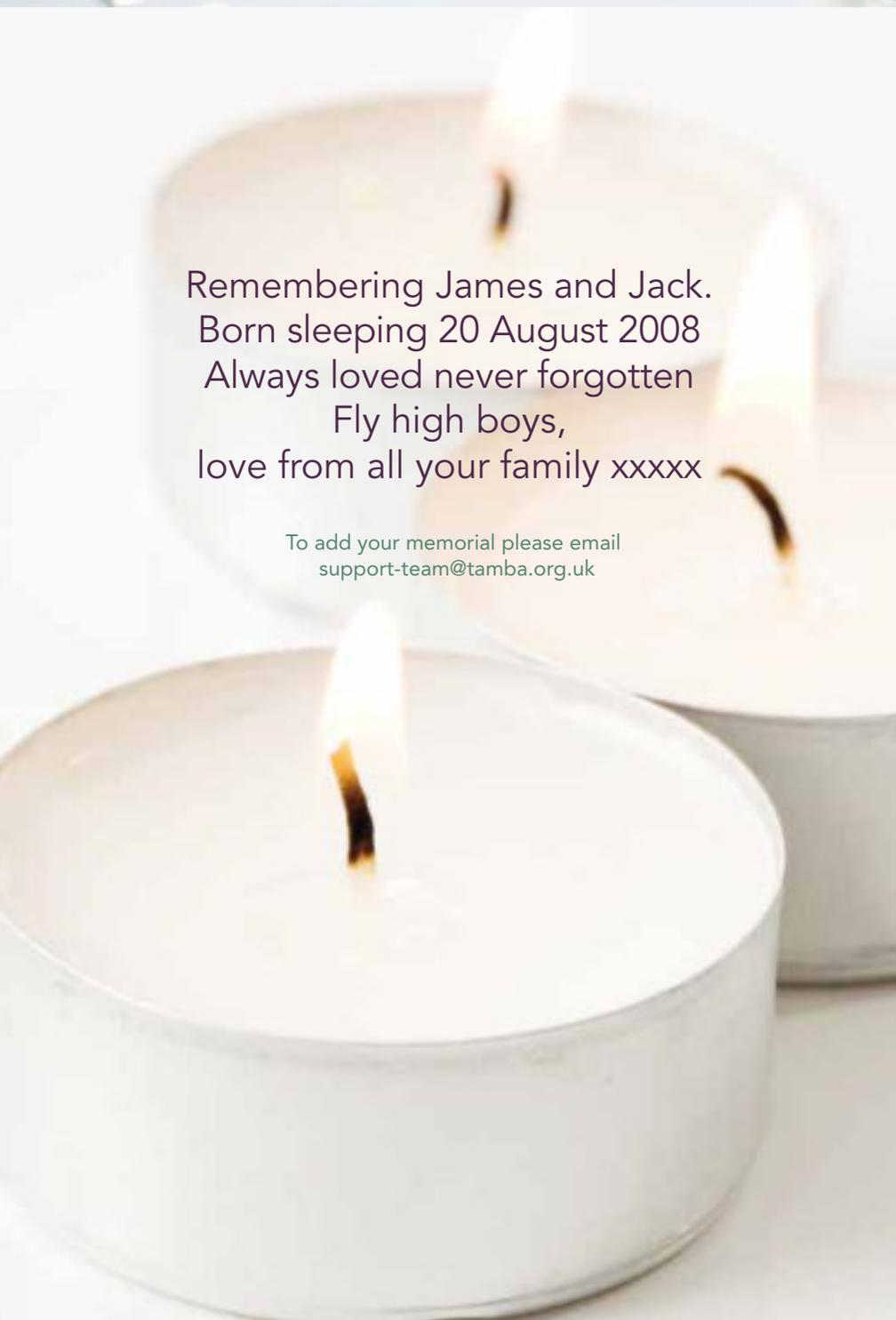
Follow us on: [facebook.com/rememmybaby](https://facebook.com/rememmybaby), email us via: [info@remembermybaby.org.uk](mailto:info@remembermybaby.org.uk), or free-phone: 0808 189 2345. [www.remembermybaby.org.uk](http://www.remembermybaby.org.uk)

# 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.



Remembering James and Jack.  
Born sleeping 20 August 2008  
Always loved never forgotten  
Fly high boys,  
love from all your family xxxxx

To add your memorial please email  
[support-team@tamba.org.uk](mailto:support-team@tamba.org.uk)

## 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. Postnatal Depression (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, 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 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 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.

## EVA AND CHARLOTTE'S STORY: SARAH MILES

When Eva died unexpectedly aged six and a half months, part of me died too. After an operation went wrong, she never woke up and died in our arms on 23 February 2012.

Thinking back, it began with the words: 'we have to move Eva to Chelsea & Westminster so they can operate on her oesophagus'. I will never forget the kind faces of the two neonatologists who broke the news Eva had been born with Trachea-Oesophageal Fistula and Oesophageal Atresia (TOF/OA). I'd never heard of TOF before, but it made sense of the high levels of amniotic fluid (TOF babies can't swallow because their food pipe hasn't formed properly) that had caused my waters to break. My obstetrician had mistakenly thought it was the early stages of TTTS. Not that I joined up all the dots at that moment. I think I nodded. My tiny girl needed an operation to save her life? Yes, please. So while Eva was blue-lighted to another hospital, I recovered on the postnatal ward with her twin sister Charlotte upstairs in NICU (neonatal intensive care unit).

### Life on NICU

After five days we were told Charlotte would be transferred to the same hospital as Eva. Nothing can prepare you for the noise, wires, incubators, machines, vigorous hand-washing and frequent expressing of NICU. It is a hidden world of fear. Eva and Charlotte were never in the same room, so I was torn between them. The nurses helped me plan my days so I could do one set

of 'cares' for Charlotte and Eva, be there for a feed, have a cuddle with each and be present at doctors' rounds. We managed to get them together on three occasions for a 'double cuddle', which was just bliss. It was only during those moments that my mind would still – there was nowhere else I needed to be; both my girls were with me.

### Charlotte's homecoming

On Day 79, it was time for Charlotte to come home, but Eva was having a tough time after the second attempted surgical repair of her oesophagus in surgery. My heart was simultaneously full of joy at bringing Charlotte home and full of fear and guilt for leaving Eva behind.

### Home vs hospital

Because of the hospital's infection control policy, I wasn't allowed to bring Charlotte back onto the unit. So I had timetabled: nights and mornings with Charlotte and afternoons and evenings with Eva. It seemed the only fair thing to do. Although exhausting, the three months that followed were our happiest times in NICU. Eva began to thrive and breathe by herself. Her weight was climbing, her head control improved and she started to smile and 'coo'. The focus shifted to development – I was determined she wouldn't get left behind Charlotte – so we devised a play programme with one of her 'aunties' (as we called the nurses). I did the same things with Eva and Charlotte: rocking them in their bouncers, reading them stories and singing the same songs while

they wriggled on their play mats. They had matching toys and the same musical nightlight soother to make things easier when they were reunited at home.

### Bringing Eva home to die

When the day of Eva's operation came around, I was terrified. Once again she had a difficult time afterwards, so I spent some long days and nights by her cot waiting for her to wake. It was 14 days later, when Eva had failed to come round, that they sent her for an MRI scan then told us the devastating news that she had suffered global brain damage and would never recover. Words cannot express how we felt. We brought her home so our girls could be together again, and she stopped breathing in our arms early one Thursday morning as the sun was rising. We'd been in NICU for 197 days. Eva died on Day 201.

'Defeated' is one word I managed to find to describe my feelings. We'd fought long and hard – all four of us – and this was how it ended? It wasn't fair.

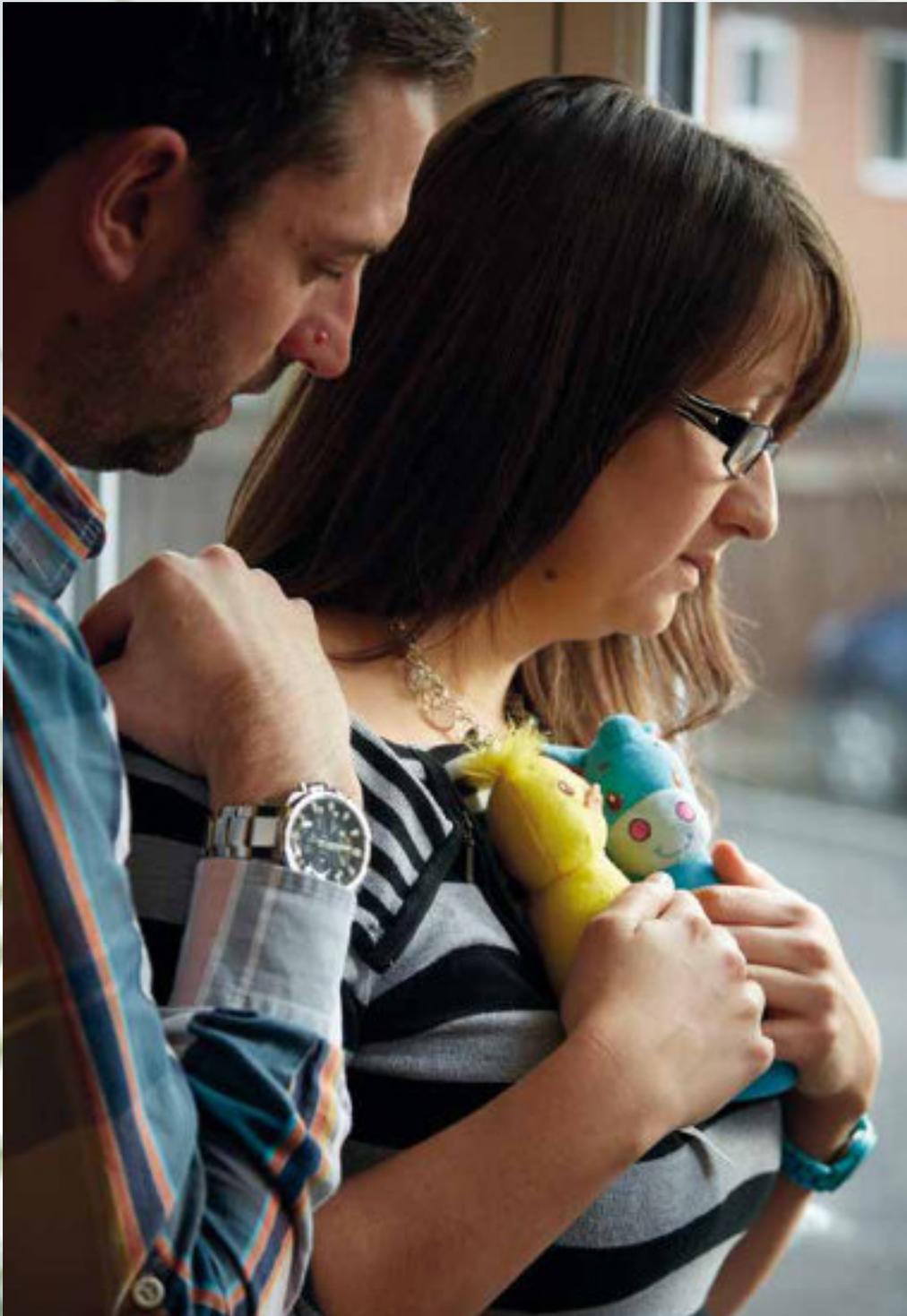
Dark days followed; I was still pulled in two directions, but this time it was between living and grieving, between keeping going and giving up. I couldn't afford to break down, Charlotte needed me. And in that way she was (and is) my salvation, my anti-depressant and my future rolled into one giggly little bundle. I was determined Charlotte wouldn't miss out on the fun stuff so we started going to baby classes. There were surreal moments when I'd be sitting in a library, singing 'Twinkle, Twinkle, Little Star' (which we played at Eva's funeral) with a smile plastered on my face, but I did it for my girls. For Charlotte in the here and now and for Eva, who I know would want her sister to be happy.

Charlotte's now five years old and, apart from a wheezy chest in winter, showing no signs of her extreme premature. She loves reading, writing and pretending to be a cat. I'm so proud of her, although it is painful to watch her meet the milestones that Eva never will. As a twin mum, I'm still torn in two between ecstasy and agony.

### Remembering Eva

It's coming up to five years since Eva died and we have always done something special on their birthday and her anniversary. I've found that creating a ritual we can repeat every year takes away some of the deliberation of planning. We visit Mortlake Crematorium with Charlotte, and now her little sister Iris, to release a balloon to 'Eva in the sky'. Last year we had a silver leaf engraved for the children's memorial tree in the gardens.

We have pictures of Eva at home and Charlotte speaks of her often, using the term 'in heaven' euphemistically (we're not religious). It can take me by surprise, such as when she asked me if Eva liked spaghetti in heaven. And it can be heart-breaking: one time she asked if heaven was too far away for Eva to come to the school disco. It's hard to explain something that I don't really understand but I try to answer Charlotte's questions simply and briefly. She is mostly matter-of-fact about it and will quickly change the subject, asking to watch TV or have a biscuit while I'm left reeling. We've never hidden our emotions from Charlotte and I've cried in front of her. It hasn't harmed her and if anything, I think she's a more sensitive, empathetic little girl as a result. Charlotte knows she is a twin (always present tense) and that Eva will always be part of our family.



## 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

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

to work when you are not 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.

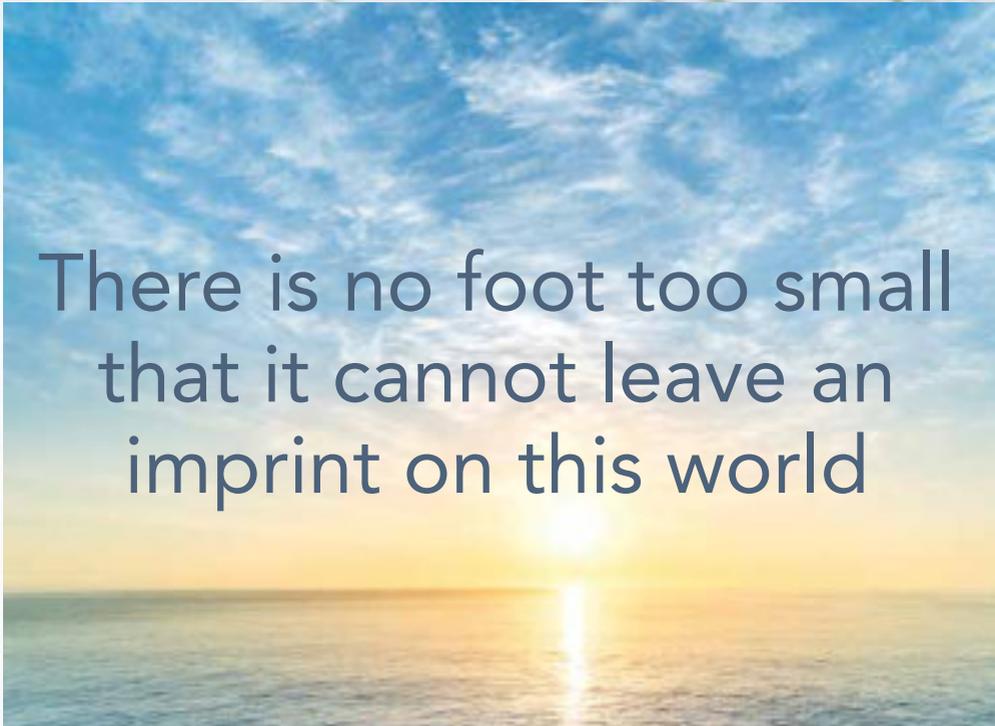
Finding out you are pregnant again is exciting, but can also be confusing. As well as joy, you may feel frightened for your pregnancy. Some parents try to protect themselves from the fear, by putting up mental barriers (ignoring the pregnancy, trying not to dream about the future). You may worry that 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.

## 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.



There is no foot too small  
that it cannot leave an  
imprint on this world

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

It is 10 years on now from my first pregnancy. It was a very surprising twin pregnancy as there is no history of twins in the family and I was very fortunate to have a straight forward one. They were non-identical and grew within millimetres of each other until the 35 week scan when one was detected to have not 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 choleostasis (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 it was decided what was best. Following monitoring on the foetal heart rate monitor, the consultant decided he was not happy with one of the twins' heart rates and I would have a c-section that day. Afterwards, my eldest, Pippa, was whisked off to SCBU as she was anaemic and I was told she would be back within the hour. I went up to the ward with Rowan. Unbeknown to me real dramas unfolded in SCBU as every time she was given blood her heart stopped. She was resuscitated successfully but still needed more blood to carry the essential amount of oxygen to live,

This continued for hours until finally I was informed and she was given to us to let her drift off. The medical staff were perplexed until blood was taken from me the following day which revealed a very high level of foetal blood in my system. 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 and heart was not strong enough to cope with the amount of blood she needed to stay alive.

Although a long time has passed, the memory of those hours with Pippa are as clear as ever although the raw emotions have changed to bearable sadness. 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 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 understand my fears despite having almost an opposite experience to me during her twin pregnancy, and 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 as 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 was so untrusting that it would work out ok.

I was determined to go back to the same hospital, with the same consultant as I wanted people to know my history when I had an appointment, so they could be understanding without me having to explain everything. I know some people want to be in a different location with new medical staff so there are no reminders. I was pleased to have the SANDS tear drop on my file so people would know there had been a loss previously, but despite this I still encountered a few occasions when I had to sit and wait for staff to read my file and ask me questions. I hated this and kicked up a fuss to only be seen by certain midwives in future. The consultant was fantastic and understood my need for reassurance of the same thing happening again and I had monthly tests for foetal blood on top of my monthly midwife appointments which really helped. It is worth fighting for what you need to make you less anxious.

I desperately needed to know the sex of the baby as I knew I would be devastated if it was a boy and 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. It was confirmed at the 20 week

scan 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 and booked one in. Emotionally I really wanted to try a natural birth as somehow it felt I wouldn't be a real woman if I couldn't give birth to a child properly. As I neared my due date I got even more anxious and the idea of a fixed date really helped, as I knew when the uncertainties would end. It was very distressing being in the same theatre waiting in the same way we did 18 months before but we managed it and the beautiful healthy baby boy we had was worth all the anxiety, distress and emotion of the pregnancy. Following the birth the staff and the hospital continued to be considerate and I wasn't in the same ward room as before. I found the pregnancy the hardest bit as I couldn't believe anyone when they said it would be all right, because that was what everyone said the first time - and it wasn't. When our healthy son had been 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! That seems a long time ago with 2 boys at junior school the trials and tribulations of babies are a distant memory.

We never forget Pippa and both boys know she is their sister. Together they helped me feel like the family we wanted to be. It was hard but definitely worth it.

## REMEMBERING OUR TWINS

### SHARON DARKE

#### 1 YEAR ON: CHARLIE AND 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

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

“ 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 ”

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

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

“ ON CHARLIE AND JOSHUA'S FIRST BIRTHDAY, WE TOOK JESSICA TO THE CEMETERY FOR THE FIRST TIME ALONG WITH FLOWERS FOR THE BOYS ”

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 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 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 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. 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

“ WE HAD THE PERFECT WEATHER FOR OUR TEN MILE WALK ON THE TWINS 10TH BIRTHDAY AND ALL COMPLETED THE WALK (INCLUDING SAMUEL AND JESSICA). IT TOOK US FOUR AND A HALF HOURS AND WE RAISED JUST OVER £1,000 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 ”

## 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 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 and 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 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 xxxxxxxxxx

## Charlie and Joshua - 17 years on...

To my gorgeous boys,

So it is Jessica's 16th birthday tomorrow and she has been celebrating all weekend with her friends. Next week you should both be celebrating and learning to drive, 17! We will be celebrating for you and remembering your short but such important lives. You are both still thought of so much and I love to talk about you both and say your names. Only yesterday Samuel explained to a visitor that our cushions are the initials of all four children; Charlie, Joshua, Jessica and Samuel. I love that Samuel and Jessica talk about you both without awkwardness and include you as part of our family.

We are still deciding what to do for your birthday. It will probably be a nice family meal and I always light a candle. We will also take some flowers to the cemetery. I am already starting to think of what we can do next year for your 18th - something special and memorable.

My Tamba role has changed recently, I now work 28 hours a month as a coordinator for the bereavement group. I love my work. I get to speak to lots of lovely people every week who have also lost a baby or babies. I feel privileged that I get to hear all of their stories and help them as I was once helped by Tamba. I am proud to be part of Tamba. It is special being a mum of twins.

Jess just got her Science GCSE result. You both would have received your GCSE results this year. You should be starting 6th form. Samuel is diabetic now, that is hard, the hardest thing since you both died in fact but he is doing amazingly. I continue to teach, mostly little ones, twins and triplets along the way. They fascinate me, I am fine with older twins, baby ones are still hard to see but I am good at coping at the time now!

Mostly my life is great now, I am very happy and appreciate every minute with my children and family. I love spending time with them. We all love holidays and days out. I love my work, especially my Tamba work and also my days teaching children. There is, however, a gap where you should both be.

As always I continue to keep your memory alive and think of you often. I love you both so much.

Love Mummy xx

This booklet has been updated, printed and circulated with money awarded to the Bereavement Support Group from Awards for All England. This is the updated version from the original booklet which was produced in 2010 from fundraising from bereaved families Sharon and Dominic Darke and Caroline and Gary Clark.



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

We hope that Tamba has been of some comfort to you at a very dark time and if you are at the stage where you feel you want to support the work we do to help future bereaved parents there are a number of ways you can do this. Some families prefer to make a donation to Tamba instead of sending funeral flowers, others ask their friends and family to make donations in memory of their lost loved ones, or make a donation themselves. Others actively fundraise (some do this sooner than others as they find it a useful way to channel their grief and deal with their overwhelming emotions).

You might not want to do anything until years after your loss and fundraising /donating is certainly not compulsory - our first aim is to support you. However, if you did want to help us we would feel very privileged.

These are some areas of Tamba's work that you might have a particular connection with, the main one being the Bereavement Support Group to support bereaved families. However, we also conduct research into TTTS and other multiple birth pregnancy complications to help prevent premature birth and to help save tiny lives in the future. If you have any queries about fundraising or donating please do not hesitate to contact [luciewigley@tamba.org.uk](mailto:luciewigley@tamba.org.uk) or [shelleysmith@tamba.org.uk](mailto:shelleysmith@tamba.org.uk).

We would like to say a huge thank you to all our amazing fundraisers and share some of their positive fundraising stories:

## FUNDRAISING STORIES

Challenges big or small, every little bit helps Tamba BSG to continue to support families.

### Bethany Morris cycled 325 miles in memory of her twin daughters

"I lost my twin daughters at 21 weeks. My waters broke and after three days I was induced because I was showing signs of infection and my babies were struggling. After a six hour labour knowing I wouldn't hear my babies cry, Harriet and Felicity were born on 2 July. They were beautiful and perfect in every way but so incredibly tiny. We were able to hold them and had a funeral for them.

We were utterly devastated but wanted to do something inspirational in their memory. Determined to turn our grief and pain into a positive we recruited some crazy friends and family to join us in remembering the girls and raise some money for charity. On their due date in November we cycled 325 miles from Crowborough, our home in East Sussex, to Northallerton in Yorkshire, where our daughters were born silently.

For most of our team, the furthest we had been on a bike was to the shops and back, so it was a real challenge. It took seven days and we covered an average of 50 miles every day.

We wanted to help other families going through the same experience and raised funds for two charities close to our hearts, one of them being Tamba. Tamba's BSG has helped hundreds of families who have suffered a loss like ours. It provides information and resources and runs a befriender's service where you can speak to others who have been through the same thing. Tamba also campaigns for better healthcare services for expectant and new multiple birth families to ensure as many pregnancies as possible have a good outcome."

### Maria Kontos Climbed Kilimanjaro

"While my partner and I were on holiday in Ibiza my waters broke and I had to be flown to a hospital in Mallorca immediately, as there was no neonatal intensive care unit there for the girls to have any chance of survival. After 4 days of bed

rest, medication and scans, as there was no amniotic fluid left, I went into labour. On 5th October 2012 our precious identical twin girls Lily and Elissa were born at 27 weeks. Very sadly Elissa passed away after 8 hours and Lily passed away after 9 days. They were so beautiful and perfect but just too tiny to survive. Our world fell apart, all of our dreams were taken away from us.

My life will never be the same again, not a day passes by where I don't think of Lily and Elissa, all the if's, whys and should have beens. I miss them so much.

I wanted to create something positive from this devastating experience and so decided to undertake a major fundraising challenge in honour of our girls by climbing Kilimanjaro to raise money for Tamba.

I wanted to be able to help other people to get the support they need when one or more of their multiples pass away. Tamba's BSG was an amazing family during this time. I hope that no one should go through the pain and heartache we have been through but if they do they have somewhere to go."

Maria is now an active befriender for the Tamba BSG group.



## Graham Fletcher cycled the Etapes Du Dales in memory of his sons Anthony and Rory.

"Libby and I lost our twin sons to twin to twin transfusion syndrome. In memory and to raise much needed funds for the charity, I chose one of the toughest cycle rides in the country to complete. With some major climbs equivalent to a Tour mountain stage and some steep and technical descents, it was an extremely difficult 110 mile route across the Yorkshire Dales in one day."

## Mark Finch and other members of Harbury RFC ran the Wolf Run

The Wolf Run is a 10K off-road event which incorporates free running, lake swims and a number of obstacles, which encourages team work to complete. Mark and his team did it twice in a row – so 20K of mud, swims, running and obstacles!

Mark chose to fundraise for Tamba because of the "Amazing support they gave to our friends following the tragic and death of their twin baby girls. We ran to provide funds for Tamba to continue the much needed assistance and support they give through these tragic times".



## Harriet Clark arranged a pub fundraiser in memory of her twins

A lively day was enjoyed by all when Harriet Clark organised a pub fundraiser in memory of her twins. There was food, drink, music and a raffle.

## John Jousiffe ran the Edinburgh Marathon to raise money for the Big Research Appeal

John says:

"In September 2015 my sister and brother-in-law had to say goodbye to their identical twin boys due to a very rare complication called OEIS (complex). In this horrendous circumstance I have seen the work that Tamba has done via their Bereavement Support Groups to assist them with their grief and felt first-hand how difficult it is for families to accept the tragic death of unborn babies. This is an issue close to my heart and so I wish to assist others by raising money for research to work towards treating the many, many complications that twin pregnancies can present."

## Emma Dunton and her husband ran in the Great Midlands Fun Run to raise money for the TTTS Appeal in memory of their son, Elijah

"On 15th February 2016 we had our 18 week scan and found out we were having identical boys! We were then dealt the blow that we were showing signs of TTTS. TTTS progressed very quickly for us and in five days we were at stage 3 and having the surgery plus two litres of fluid drained under local anaesthetic. We were scanned afterward and the good news was that the boys survived the surgery! On February 29th (20 +1 weeks) we went for our follow-up scan and my little boy lay on the screen not moving, no little wriggles, no little bubbles, and no heartbeat. That image will never leave my memory. He was given the name Elijah. The next 15 weeks went by in a daze and on 16th June 2016 we welcomed our beautiful boys. We are raising money so that hopefully, in time, no other parents have to lose their babies and no other brothers or sisters have to grow up without their twin."

If you have been inspired by the stories and would like to do something to actively fundraise then please contact [luciewigley@tamba.org.uk](mailto:luciewigley@tamba.org.uk)

If you would like to make a donation specifically to the BSG then please visit [www.tamba.org.uk/bereavement/donation](http://www.tamba.org.uk/bereavement/donation)

To make a donation towards TTTS or other life saving research please visit [www.tamba.org.uk/Get-Involved/Fundraising/How-You-Can-Help/Donate](http://www.tamba.org.uk/Get-Involved/Fundraising/How-You-Can-Help/Donate)

Alternatively send a cheque, payable to Tamba, to the following freepost address (remember to tell us if you want your donation to go to BSG, TTTS or other research):

**Business Reply License Number RTLC-ZXEA-KRYU**  
**The Twins & Multiple Births Association**  
**The Manor House, Manor Park, Church Hill, Aldershot, GU12 4JU**

# INFORMATION FOR HEALTH PROFESSIONALS

Multiples make up approximately 1.5% of pregnancies in UK with numbers rising significantly over the past 20 years. Each multiple birth baby is twice as likely to be stillborn as a singleton, and almost five times more likely to die in neonatal care. The latest figures from the Office of National Statistics (ONS) show multiple birth stillbirth rates rose by 13.6% between 2013 and 2014. Research shows that when the NICE guidelines are implemented in full, the rate of stillbirths, neonatal deaths and C-sections is reduced by up to a third. However only 10-18% of UK units have implemented these guidelines in full.

Join Tamba's Health Professionals list to get FREE access to:

- Online access to multiples specific CPD videos
- Monthly newsletter
- Access all areas Tamba website
- Download Tamba resources

To access any of the above services please email [maternityengagement@tamba.org.uk](mailto:maternityengagement@tamba.org.uk) or go onto [www.tamba.org.uk/health-professionals-welcome](http://www.tamba.org.uk/health-professionals-welcome)



## THE BUTTERFLY PROJECT – SUPPORTING PARENTS WHO HAVE LOST A BABY FROM A MULTIPLE PREGNANCY.

Newcastle Neonatal Research Team spoke to parents who have suffered the loss of a baby, either before or after birth. Their focus was on multiple (twin) pregnancies where one baby died and at least one baby survived. They also spoke to health care professionals such as midwives, neonatal nurses and doctors. If you are a health professional and would like to join the butterfly project, please contact them and they will send you a free teaching pack of powerpoint slides, handouts and guidelines you can use on your intranet. They can send you Butterfly cot cards and parent letters. They are focusing on staff education and practice but if you are a parent and would like to find out more please contact <http://www.neonatalresearch.net/butterfly-project---about.html>

As part of the butterfly project they provide parents with an information leaflet. Parents are asked if they would like the staff to place a butterfly symbol next to the cot, or inside the incubator. Parents are asked if they would like to write the name of the twin or triplet who died on the butterfly sticker. A sticker could also be placed on the outside of the medical notes of the surviving twin, or the medical notes of the mother if the loss occurred before birth.

Parents report that sometimes they feel that their loss is underestimated because of a tendency of others to try to be positive and focus on the surviving twin. Typically they welcome being given 'permission' to grieve for their loss, while celebrating their surviving baby. One parent described it as 'just brilliant' because the nurse always talked about 'them' and 'she used his name as well'

Health Professionals can access a free webinar recording with the Newcastle team via the free Tamba CPD section <https://www.tamba.org.uk/health-professionals-welcome>

# AND FINALLY...

If you have recently lost one or more of your multiple birth babies/children, 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.

A huge thanks to all the volunteers, staff and families who have helped to update this booklet. But also those who help support bereaved families through their journey. We know that so many people find this support helpful.

Keith Reed CEO of Tamba

## ACKNOWLEDGEMENTS

Thanks to Tamba Bereavement Support Team in coordinating and overseeing the editing and production of this update to the booklet. Helen Turier, Support Services Manager, Louise Bowman, Twinline and Support Groups Coordinator and Sharon Darke, Bereavement Support Coordinator.

Thank you also to Tamba Support Team, Communication Team and Fundraising Team for their contributions.

We would very much like to thank the following parents for sharing their personal experiences and for providing ideas, suggestions and corrections on the booklet drafts: Clare Norman, Jay Harper, Claudia Belardo, Tracey Kirby, Shelley and Paul Howard, Sally Fox, Lisa Osbourne, Matt Froud, John Garden, Richard Boyd, Jeanne Reily, Sarah Miles, Nicky Chester and Sharon Darke. We would also like to thank Grandparent Sue Bamblett and Sibling Christine Spoors for sharing their experience too.

Thank you also to the parents, families and friends who have taken on challenges and fundraised for Tamba BSG and to those who have shared their stories in this booklet. Bethany Morris, Maria Kontos, Graham Fletcher, Mark Finch, Harriet Clark, John Jousiffe and Emma Dutton

## RECOMMENDED READING

To find out the rights of bereaved parents to maternity / paternity leave you can take a look at Maternity Action - <https://www.maternityaction.org.uk/advice-2/mums-dads-scenarios/miscarriage-stillbirth-and-neonatal-death-rights-to-time-off-and-pay-for-parents/>

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.

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.

Kate Polley

'The Story Of...' books. Personalised twin loss story books. For families who have lost one or both twins. [www.personalisedchildlossbook.com/sam-and-finn/](http://www.personalisedchildlossbook.com/sam-and-finn/)

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## HOW TO GET HELP – ORGANISATIONS OFFERING BEREAVEMENT HELP

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

Manor House, Church Hill, Aldershot

Hampshire, GU12 4JU

Office: 01252 332344

Twinline: 0800 1380509

(10am-1pm and 7-10pm 365 days a year)

[www.tamba.org.uk/beravement](http://www.tamba.org.uk/beravement)

### ARC (Antenatal Results and Choice)

ARC, 345 City Road, London, EC1V 1LR

Helpline: 0845 077 2290 or 0207 713 7486

- Mon-Fri, 10am-5.30pm.

Admin: 020 7713 7356

Email: [info@arc-uk.org](mailto:info@arc-uk.org)

### BLISS

(For babies born premature or sick) 2nd

Floor, Chapter House, 18-20 Crucifix

Lane, London SE1 3JW [www.bliss.org.uk](http://www.bliss.org.uk)

Office: 020 7378 1122

[ask@bliss.org.uk](mailto:ask@bliss.org.uk)

Helpline 0808 801 0322

### Child Bereavement UK

Child Bereavement UK (Head Office)

Clare Charity Centre

Wycombe Road, Saunderton

Buckinghamshire HP14 4BF

Tel: 01494 568900

[support@childbereavementuk.org](mailto:support@childbereavementuk.org)

Helpline: 0800 0288840

[childbereavementuk.org/](http://childbereavementuk.org/)

### Child Death Helpline

Call our freephone helpline on 0800 282 986 or 0808 800 6019 if calling from a mobile.

Monday to Friday 10am to 1pm

Tuesdays 1pm to 4pm

Wednesdays 1pm to 4pm

Every evening 7pm to 10pm

[contact@childdeathhelpline.org](mailto:contact@childdeathhelpline.org)

[www.childdeathhelpline.org.uk](http://www.childdeathhelpline.org.uk)

### Compassionate Friends

(Offers friendship to grieving parents who have lost a child of any age) Head office:

14 New King Street,

Deptford,

London SE8 3HS

0345 123 2304 Helpline

0288 77 88 016 NI Helpline

[helpline@tcf.org.uk](mailto:helpline@tcf.org.uk)

### CRUSE

(Somewhere to turn when someone dies)

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

### Lullaby Trust

11 Belgrave Road London

SW1V 1RB

Telephone (general enquiries):

Tel: 020 7802 3200

[office@lullabytrust.org.uk](mailto:office@lullabytrust.org.uk)

Bereavement Support: 0808 802 6868

[support@lullabytrust.org.uk](mailto:support@lullabytrust.org.uk)

### The Grandparents Association

Moot House, The Stow,

Harlow, Essex, CM203AG

Tel: 0845 4349585.

(10am-4pm Monday to Friday)

### Lone Twin Network

(Offers a network of contacts and support to adults whose twin has died at whatever stage of life)

54 Ventnor Avenue,

Hodge Hill, Birmingham, B36 8EF

### Miscarriage Association

(Includes Ectopic Pregnancy Support Network)

17 Wentworth Terrace

Wakefield WF1 3QW

add email address in -

[info@miscarriageassociation.org.uk](mailto:info@miscarriageassociation.org.uk)

### Multiple Births Foundation

Hammersmith House, Level 4, Queen

Charlotte's & Chelsea Hospital,

Du Cane Road,

London, W12 0HS

Tel: 020 3313 3519 / 020 8313 3519

[mbf@imperial.nhs.uk](mailto:mbf@imperial.nhs.uk)

### Stillbirth and Neonatal Death Society (Sands)

Victoria Charity Centre,

11 Belgrave Road

London, SW1V 1RB [www.sands.org.uk](http://www.sands.org.uk)

Our main office is based in London, and is open between 9.30am-5.30pm,

Monday to Friday.

Tel: 020 7436 7940

Sands Helpline

Tel:020 7436 5881 [helpline@uk-](mailto:helpline@uk-sands.org)

[sands.org](http://sands.org)

### Winston's Wish

(For children who have been bereaved)

Helpline: 08088 020 021

(9am-5pm weekdays)

[www.winstonswish.org.uk](http://www.winstonswish.org.uk)



Twins and Multiple Births Association (Tamba)

Tel: 01252 332344 | Twinline (Helpline) 0800 138 0509 | [www.tamba.org.uk](http://www.tamba.org.uk)

Registered charity no. 1076478 | Scottish registered charity SC041055 | Company No. 3688825

**Tamba**  
TWINS & MULTIPLE BIRTHS ASSOCIATION