twin triplet support

Advice for Healthcare Professionals

ENHANCING BEREAVEMENT CARE

This leaflet is written with the help of bereaved parents who have sadly experienced the death of a baby or babies from a twin or triplet pregnancy.

It is aimed at healthcare professionals who may come into contact with a family before, during or after the death of a baby or babies from a multiple pregnancy. For example:

- Sonographers
- Hospital/Community midwives
- Doctors
- Paediatric and neonatal nurses
- Health visitors
- Allied HCPs
- GPs
- Admin and reception staff

The importance of how healthcare professionals (HCPs) act and the language they use during someone's care cannot be underestimated. It can often have a significant impact on someone's grief journey.

In your role as an HCP, you may regularly support families experiencing baby loss. However to each individual family you will often be a significant person on their grief journey, and it's likely they will remember you and everything you do for them in that time, for many years to come.

SPECIFIC CONSIDERATIONS FOR MULTIPLE PREGNANCIES

When one or more of a family's twins or triplets die it can be a very traumatic time for parents, other siblings and the wider family. Sometimes the death will be expected but at other times it will be sudden and unexpected.

Loss within a twin or triplet pregnancy is often complex as there are many variables and possible outcomes.

Each person's experience of twin or triplet loss will be unique to them and there is no "one way" of grieving. It can be an extremely complicated type of grief with intense emotional reactions which can be confusing, and at times, may be quite frightening.

Grief may be further complicated when one twin/triplet dies and one or more lives. The parents then have to deal with their feelings of sadness about the baby who has died while simultaneously trying to remain hopeful that the other baby/s will be ok.

It is essential therefore to have kind, caring and honest HCPs to advise and support families with the decisions that they will need to make. These families are often in shock and find themselves in situations that they have never imagined. It can be scary and taking in information can be hard. It is important to have HCPs who are able to give parents the appropriate guidance regarding the practical arrangements they may need to make and offer care that supports their individual family's needs.

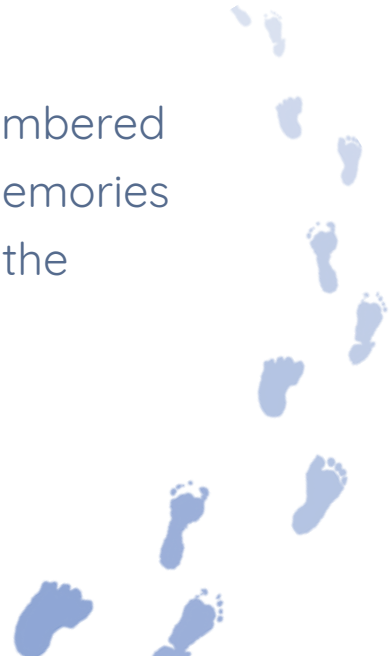
> “It was such a challenge to have constant mixed feelings of profound grief for Sam who had died, and intense joy for Ben who was alive and doing well. ”

> “After the loss of my second-born triplet, I was blindsided by the experience of having to navigate the emotions of immense joy coupled with crippling grief. ”

The actions and conversations you have with a newly bereaved family in these moments will have a lasting impact on their grief journey.

Good care, guidance and advice can minimise feelings of uncertainty and anger when the grief sets in, enabling a more gentle journey of learning to live with their loss and grief. While these experiences can feel daunting and even traumatic at the time, professional and empathic care will help parents to look back on these moments with a greater degree of peace and comfort.

You, as health professionals, will often be remembered in these families' bereavement journeys and memories for the huge difference you made in what was the hardest and most intimate time of their life.



BE OPEN AND HONEST

Parents need to be kept informed of what is happening with their babies.

- It can be difficult for parents to take in lots of information so try to use clear and concise explanations.
- Use the correct language to ensure that it is clear what the parents are being told. For example, if the baby is unable to survive, ensure that it is sensitively but clearly communicated to the family.
- Reflect the language that parents are using - death or loss, twins or triplets, name of baby or babies used etc.
- Consider that they may already have experienced the death of one baby, or they may know that one or more babies will not survive.
- Give parents time to make informed decisions; it can be very difficult to take in too much information and they will often need time to process it.
- Ensure that you read the previous notes.

> “Being spoken to about reduction of my triplets as soon as finding out about them, then repeatedly being asked about it, was hard.”

MAKING MEMORIES

For many parents this will be their first experience of loss and they may not know what they want to do so it can be helpful to offer them choices and guide them with their decisions.

Often parents may be experiencing shock that their baby or babies have died, and may be finding it difficult to make decisions or to feel they know what 'normally' happens in these situations. Give them lots of help in knowing what the options are and what other families have found comforting in the past. Guide them to make decisions they will feel comfortable with in the future. Consider that they may value support with memory making for more than one baby. They may want to have the same options each time.

> **"It was so important to me that I was offered the same things with Joshua as I had with Charlie after he died 6 days later."**

Offer as much memory making as possible with each family: bathing, taking photos, offering photos of both/all babies together if at all possible, photos of the whole family, locks of hair, taking hand and footprints or casts, holding and dressing the baby or babies etc. Offer the chance for other family members and siblings to see the baby or babies where possible.

Often the memories that are made in hospital will be all that the family has of their twins or triplets before they all die, or of them together as a family before one of them has died.

Ensure that the parents are given enough time to make their decisions based on the information that they have been given. They will need time to reflect and consider their options. Give parents permission to change their minds at any time about any memory making even if they have declined something previously, when possible.

Consider the condition, size and gestation of the baby or babies and explain any concerns sensitively to the parents about what memory making is possible. Ensure that any visible abnormalities are sensitively explained to the parents by an experienced HCP, and consider that the baby can sometimes be wrapped if the parents would like the abnormality to be concealed.

In most hospitals, charities, such as 4Louis and Sands provide memory boxes which can be used during memory making. Aching Arms provides teddy bears for families who experience baby loss. Remember my Baby offers a complimentary gift of baby remembrance photography to all UK parents experiencing the loss of their baby before, during or shortly after birth.

Parents may not always be able to see their baby or babies, particularly when there has been an early pregnancy loss. In these cases HCPs should explore other ways of memory making such as including the baby or babies in a book of remembrance and ensuring parents know about the Government-issued Baby Loss Certificates.

www.gov.uk/request-baby-loss-certificate

UNIQUE COMPLEXITIES WITH LOSS FROM A MULTIPLE BIRTH

When there is a surviving twin or triplet ask the parents how they would like you to refer to their babies. Always use the babies' names, providing the families want you to. If you are unsure, ask them. A purple butterfly should be offered to the family for the surviving twin's cot or incubator. We work closely with the Butterfly Project providing educational materials and eLearning courses for HCPs www.neonatalbutterflyproject.org/ and one of our partner charities The Skye High Foundation provides Butterfly cot cards and other resources www.theskyehighfoundation.com/

The Purple Butterfly cot card was co-created with parents and can be placed in an incubator or cot, or nearby, in memory of any twin or triplet sibling/s who died. The cot card is used in conjunction with a poster that is placed around maternity and neonatal units, which explains the meaning of the purple butterfly. The butterfly cot card allows families the opportunity to make others around them aware of the journey they are going through. Most families want the twin that has died to be mentioned.

> **"It was so comforting to hear medical professionals use my twin son's name after he died when I was in hospital with his surviving twin brother. It made me feel like he hadn't been forgotten. It makes a huge difference to a bereaved parent to hear their child or children's name/s especially after they died. Their existence in the world (however short) is important and to have that acknowledged by healthcare professionals leaves a lasting impact."**

Ensure that your words are chosen carefully whenever you are communicating with the parents. Use kind and sensitive language when looking after bereaved families at all times particularly when breaking bad news, during memory making and at the time of discharge from the hospital. Non-English speaking parents should always be offered an interpreter when required.

This is particularly helpful to think about when they are still pregnant, but one has died in utero. Consider how you refer to the pregnancy of a twin or triplet when a baby has died in utero. Most families do not want their twin pregnancy referred to as a singleton pregnancy or a triplet pregnancy as a twin pregnancy.

> **"The first day after Louis passed away I went in for an appointment and it was during the weekend so my usual team were not there. A midwife called out "the lady with the twins".**
>
> **I didn't turn around. She snapped it again and I didn't turn around because in my head, I didn't even think she'd be talking to me. She came over to me in a waiting room full of people and said "you've got twins?" And I said that I had triplets.**
>
> **She loudly said "one's dead, they're twins" and crossed out the triplets on the antenatal card we took in for each visit."**

Parents may have lots of questions and concerns about what the baby that has died will look like if he/she is born later. It can be helpful to talk this through with an experienced member of the team such as the bereavement midwife or Fetal Medicine consultant and to consider what will happen at the birth and afterwards. It is important to remember that sometimes there can be regrets that cannot be changed and are difficult to live with.

> **"I was encouraged not to see one of my twins because of what he looked like. It is my biggest regret. I think if I had been gently enabled to see my baby whatever he looked like, it would have helped my grief journey and not left me with wondering for the rest of my life."**

LEAVING THE HOSPITAL

When parents leave the hospital it can be difficult for them to take in everything they are being told. Written information on what happens next i.e. the funeral options, ongoing support at home and follow up should be given to parents on discharge as well as signposting to national and local support, and counselling organisations. It can be helpful for the parents to look through later when they may feel more ready to seek support. A follow-up appointment should be offered to all parents who have experienced the death of a baby. The appointment is an opportunity for parents to receive the results of any investigations such as a post-mortem, ask any questions they may have about what happened and to discuss management of a next pregnancy.

> **"I couldn't believe I was leaving the hospital without my babies and with two memory boxes instead."**

CONTINUING SUPPORT IN THE COMMUNITY

Follow-up care is, unfortunately, highly variable. It can be helpful to know what professional help is available in your area, as well as any charities or local hospices that offer support, so that you can signpost families.

Many families will remember the healthcare professionals who looked after them and their twins and triplets for many years afterwards. In our experience of supporting bereaved twin and triplet families, we find that those that have access to a wide range of support such as counselling, charity services, peer-to-peer support, maternal mental health services etc. manage to navigate their way through the early stages of grief feeling less isolated and better supported.

"My experience with the health professionals when we lost the boys was overwhelmingly positive. I vividly recall their compassion as if it were yesterday.

I remember the lovely midwife who was the first in the room when Jacob arrived unexpectedly, the consultant who shed tears when he passed away shortly afterwards, and the midwife who hugged and cried with me when George was stillborn four days later. Losing both boys under such heartbreaking circumstances was unbearable, but the kindness I received was such a support, even though I didn't fully realise it until later.

I wish I could go back and thank each one of them, so they would know the huge difference they made during the saddest of times."

> **“I was inpatient in hospital for 7 weeks during my twin pregnancy, throughout the time when sadly both my twin boys died. In that time I got to know so many of the staff and built up relationships with many of them. I used to look forward to my daily chat with the lovely cleaner on my ward. I will never forget the doctors and nurses who looked after me in that time, and those that took that extra bit of time, care and acknowledgement of what had happened to my twin babies.”**

WHERE TO FIND HELP

Inform parents about some of the support that is on offer for them once they leave the hospital. Peer-to-peer support can be extremely helpful afterwards, especially with twins and triplets where it is a unique and complicated grief.

> **“Grieving for a twin, triplet or more can be a very lonely experience and to be able to connect and speak to others who fully understand really helps.”**

Footprints Baby Loss is a bereavement charity that provides vital support to parents and families who experience the death of one or more of their twins or triplets before, during or after birth.

We are a charity run by bereaved parents, for bereaved parents.

Our support is provided by those who have had first-hand experience of twin or triplet loss. We understand the value of having a safe space to be able to communicate with someone who has been through something similar, and provide a kind, caring and inclusive approach with our bereavement services.

We provide bereavement support in the form of befriending, online support groups and a private online community group.

www.footprintsbabyloss.org

> “Having a befriender who has experienced similar loss from a multiple pregnancy is a lifeline. It provides an invisible understanding and connection that is a huge comfort.”

We have a list of useful contacts and other charities on our website.

> “When working with bereaved families remember the importance of never downplaying what the parents have experienced, are going through or what they feel. If you don’t know what to say, or do, be honest.
>
> Sometimes saying “I’m really sorry, is there anything I can do to help” is enough. And never use the phrase “At least you’ve still got one”. Having a surviving baby, or older child, can never replace the grief and loss parents feel when a baby dies.”

Nick Embleton, Professor of Neonatal Medicine, Newcastle University and Consultant Neonatal Paediatrician, Newcastle Hospitals NHS Foundation Trust.

“Far too many parents have told us that having to repeatedly retell their experience caused them unnecessary distress and how they felt that more effective communication across teams could have prevented this.

Before any meeting with parents HCPs should prepare themselves by carefully reading the hospital notes and noting the type of loss/losses, the circumstances and most crucially the baby/babies names.

A comprehensive awareness of the history and also of any previous losses will assist the HCP in providing a compassionate and sensitive care experience, without the individual having to repeatedly recount the story of their loss.

This is particularly important to note when meeting with parents who are presenting in a subsequent pregnancy.”

Sam Collinge, Bereavement Lead Midwife (George Eliot Hospital NHS Trust) and Co-Lead and author of the Independent Pregnancy Loss Review.

Thank you to Dr Nicholas Embleton, Samantha Collinge and our Footprints families, for their contributions to the leaflet.

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Charity No. 1206261