Loss in a Multiple Pregnancy

A Guide for Staff





Irish **Neonatal Health** Alliance

Introduction

Over the last two decades, the number of multiple births has increased dramatically because of fertility treatments, and healthcare professionals are encountering loss in multiple births much more often. Doctors, paediatricians, midwives, allied health professionals, health-care assistants, chaplains and counsellors and other staff who come in contact with bereaved parents require guidance on how to provide sensitive and informed care when there is loss in a multiple pregnancy. The term 'twin' is used in this booklet, but the information is also relevant to triplets and higher order multiples.

Here is some advice from Renée Dilworth, Chaplain, the Coombe Women and Infants University Hospital, Dublin

Loss of one or both twins is a significant bereavement for parents. It is so important for us as staff to offer our condolences to families who are grieving the loss of a baby in a multiple pregnancy. Most parents want their twin who has passed away to be acknowledged and remembered along with their surviving twin. From my experience as a chaplain, parents really do appreciate a listening ear and empathy from staff.

When one twin dies, the joy that parents experience on arrival of their living baby is clouded by loss of their twin brother or sister. Parents often feel deprived of the specialness of being the parent of living twins. Memory making with both babies - those who have passed and those who have lived - is important to bereaved parents. I believe that the opportunity to get to hold their baby who has died and their baby who has survived is a key part of the grieving and healing process.

If parents find out that one of their twins has a medical condition where he or she might not live for long or that one of the babies has died in utero, I would encourage staff to support parents to embrace and bond with both of their babies right now. I think this really helps parents to heal.

The sense of joy, excitement, and anticipation that parents experience when they are having two or more babies is lost when one or more babies die. Parents grieve for the loss of what should have been - both of their twins here with them to enjoy life together.

I will finish with a verse from the poet Christy Kenneally:

"If you would honour me then speak my name and number me among your family."

How bereaved parents might be feeling

Bereaved parents who have experienced loss in a multiple pregnancy might be feeling:

- Loss of their status in society as the parents of twins. If there is a surviving twin, parents might find it upsetting if they feel that their twin who has died is being forgotten.
- Great sadness that they might no longer be acknowledged as the parents of twins.
- Broken-hearted, for their own loss when they see twins and other women who are expecting twins.
- Upset for their surviving baby about the loss of their future relationship with their twin brother or sister.



Grace and Susie's Story

On the 7th April 2017, we welcomed our angel Grace and our beautiful twincess Susie into this world, rather suddenly and unexpectedly.

I was 30 weeks pregnant and had arrived at the hospital at 6.10am because I had reduced movement and when a scan was done, I was told that our twin 2, Grace, did not have a heartbeat. It all happened very quickly, and the twins were delivered at 6.51am and 6.52am, just 40 minutes from when I arrived at the hospital. The hospital's doctors and nurses were amazing that day.

My first memory after waking up after the c-section was seeing my husband Mark in the recovery room with tears in his eyes but also his phone in hand to show me the first photo of Susie who he had just seen in the Neonatal Intensive Care Unit. We were told that the next 48 hours were critical for Susie, so that became a great worry for us. I also got to hold Grace straight away. Our beautiful amazing Grace who looked so perfect.

Words cannot express the impact that the medical staff had on our whole journey. It meant a lot to us when the nurses who I had got to know from attending the twin clinic fortnightly came up to visit me and Grace after the birth. They were very sensitive and asked about Grace and commented on how beautiful she was. I remember how one nurse realised that I did not want to leave Grace in the room alone and she offered to sit with her while I went up to the Neonatal Intensive Care Unit to check on Susie. Another nurse who was looking after Susie in Neonatal Intensive Care Unit arranged for her to be safely brought to another room in the unit, so that we could bring Grace to see her sister and lay beside her.

We got to take precious photographs on our mobile phones of our twin daughters together and seeing Susie snuggle up to Grace is a memory both Mark and I will cherish forever.



My time in hospital was divided between wanting to spend as much time as possible with Grace and trying to be with Susie and willing her to get stronger. It helped a lot when the hospital gave me a tablet screen that allowed me to see Susie in the Neonatal Intensive Care Unit while I stayed with Grace. In an odd way, it was easier to see Susie on a screen as she looked bigger and less stressed from all the machines she was connected to.

Grace will always be in our hearts and is with us everywhere.

Her Grandma Mary is minding her for us in heaven and she is looking out for her sisters who have a very special guardian angel.

Our Amazing Grace.

Bernadette, Grace and Susie's Mammy



Acknowledging the loss of a twin

When a baby has died in a multiple pregnancy, most bereaved parents appreciate it when members of staff acknowledge their twin who has died. However, it is best to check the medical notes or talk to other staff to find out each parents' preferences.

Take time to check the notes to find out:

- The background story to the parent's loss,
- Whether or not the parents want to acknowledge or talk about the twin who has died right now. This can change over time or on a day to day basis.
- The names of the babies rather than referring to them as twin 1 and twin 2, for example.

It is important to recognise that every parent will have different experiences and needs, and therefore their situation and preferences should be recorded. A staff member should be given responsibility to record this information and share it with their team at handover.

It is important for staff to listen when parents want to talk about their loss. Parents appreciate compassion and support from staff. Talking to parents is just as important as offering them practical help. Try not to worry about "saying the wrong thing" and just give parents an opportunity to talk. Ask parents if there is anything else that you can do to help. Parents will appreciate you giving them your time to listen.

If parents would like acknowledgement of the loss of one of their twins for example, staff could say something like "Congratulations on the birth of your, baby but I am so sorry that your other baby has died". It is very important however to avoid focusing on the positive by saying things like "at least you have another baby" or "let's stay positive and focus on your surviving baby" because bereaved parents may feel that they are not allowed to grieve for what they have lost and that their loss is not important. In reality, a surviving baby will never replace the baby that has died. In fact, each milestone and special event experienced by the surviving baby can emphasise what the family is missing out on.

It is important also to remember that even if a twin has died early in the pregnancy, staff should check the medical notes to ascertain if the parents want to acknowledge each baby's existence. Parents will have often bonded early in their pregnancy and may want to acknowledge the baby who has died. It is helpful for parents to see familiar faces who know their story and have met their babies. Where there is a changeover of staff or where families need to be transferred to another ward or department, make sure to communicate key information to other staff at handover. This will avoid parents having to retell their story over and over.



Brian and Nathan's Story

The day that Brian died is the day my life changed forever.

In 2013, when I went for a routine scan of my identical twin boys, I was expecting to have a discussion with my consultant about when we would be delivering the babies and what my options were. Instead, while being scanned, the nurse saw something that she thought was not right. A second opinion was sought and sadly we were then told that there was irregular blood flow to the twins due to Twin to Twin Transfusion Syndrome (TTTS). My consultant decided to admit me to hospital and deliver the babies in two days' time. We were checked into the hospital and were monitored. Suddenly, however, I was told that I needed an emergency c-section.

I was rushed to theatre. Doctors and nurses were talking to me, telling me things, asking me questions, while I was being pushed at high speed in a wheelchair down to theatre. I did not have time to think about what was happening. Everything was moving so fast. I was given a general anaesthetic and that is the point of no return.

When I woke, my life went into a spin when I was told that one of my beautiful twin boys had died and his identical twin brother was in the Neonatal Intensive Care Unit. All I could think about was how could this happen to me. Bad things are not supposed to happen to good people and

no one, I mean no one, should have to go through the loss of a baby and the pain that it brings. My grief was even more complicated because there was still one baby for me to care for. I worried about how I was going to grieve for one baby while at the same time care for a tiny premature baby just after having emergency surgery that physically wipes you out.

I came home from hospital with no baby in my arms because one baby was in the morgue and the other baby was in the Neonatal Intensive Care Unit.



When I got home, I decided to get rid of the twin stuff. I bought a single buggy and preemie baby clothes. I also had to arrange a funeral, wait for post-mortem results, pick out a headstone and at the same time, travel in and out of the hospital to see, feed and care for our surviving twin. To say that my head was a mess is an understatement, but I had great support from my partner, our families, and our friends. I tried to enjoy seeing our little boy thrive and thrive he did. But there were so many emotions that were attached to losing Brian.

We now have a funny, strong, and loving little boy that I am eternally grateful for. However, there should be two of them, looking the same and having a bond that only twins can have. Every special event, milestone and birthday is overshadowed by the fact that Brian is missing.

I answer questions daily from Nathan as to why his brother isn't here and why he died. I have learnt that Brian is a part of me, a part of my story and a part of why I am who I am today.

Elizabeth, Brian and Nathan's Mommy



Referring to the baby who has died

Staff should use appropriate and sensitive terminology in healthcare records and on identification bracelets when referring to each baby when there has been a loss in multiple pregnancy.

It can be upsetting for bereaved parents if 'Twin 1' is no longer recognised as a twin and is now called 'Baby X', as if the pregnancy were a singleton pregnancy for example. It can also be upsetting if a healthcare record suddenly only records 'Twin 1' without mentioning 'Twin 2'.

If one triplet has died, parents can get upset if their surviving babies are referred to as 'twins'. Although some parents may prefer this, where a triplet died early in pregnancy. It is best to ask the parents for their preference.

Find out what the wishes of the parents are in relation to referring to their baby who has died and record this in the medical notes.

Never assume what you think the parents might want - always ask them first.

Butterfly Alert Symbol

Sometimes, while in hospital, staff and visitors may not know that a surviving baby is a twin or triplet. To address this, the *Irish Neonatal Health Alliance* launched the **Butterfly Alert Symbol** and accompanying poster, which has been sent to all 19 maternity units throughout Ireland. This symbol indicates that a baby, on whose cot it is displayed, is the survivor of a multiple pregnancy.

The butterfly alert symbol is considered to be international best practice and staff can download it for free from the Irish Neonatal Health Alliance website at: www.inha.ie/family-info/

Staff should ask parents if they would like the symbol to be placed on the outside of their surviving baby's incubator/cot whether the baby be on a neonatal unit, a ward or a private room. Show the symbol to the parents and explain why it is used.



Bereaved parents should also be given the option for the symbol to be placed on the door of their private room. Again, with the parents' permission, it can be 'clipped' to the mother's and her surviving baby's medical records to identify the parents as bereaved.

The symbol can also be offered to parents at a time when they are anticipating bereavement as well as following the death of their baby.

It is a good idea to display the symbol along with its poster in a public area of the hospital to increase awareness of its meaning among staff and visitors.



Liam and Grace's Story

On 23 March 2018, my biggest wish in life came true when I became a Mammy to Liam and Grace.

As I had gone into premature labour at 22 weeks 6 days, Liam died just before he was born, and Grace lived breathing on my chest for 31 minutes before joining her twin brother. Despite the endless pain and heartache of living without my precious son and daughter, I love talking about them and I feel proud to be their Mammy every day.

I remember it was a few weeks after Liam and Grace were born that I learned what the word midwife means "to be with woman". I did not know that on the 22nd and 23rd March but I certainly felt it. From the moment we went into hospital, I was treated with the best of care. Sadly, over the last few years, when I had three miscarriages, I have had experiences where the care I received was lacking, so I have experienced both the good and bad. But what a difference it makes when it is good.

There were three lovely midwives and a doctor who cared for me at different times while I was in labour. I am sure when they signed up to be healthcare professionals, they looked forward to delivering lots of healthy babies and the absolute joy of being part of something so wonderful each day. Looking back, I think they realised very early that my babies were coming, and they would not survive. But they gently took our lead and gave us the time and the space we needed to accept that our worst nightmare was becoming true. They really guided and supported me through every step of my labour but I think it was after my beautiful babies were born that they really cared for us.

My favourite memory just after Liam and Grace were born is the midwives congratulating me on becoming a Mammy and what beautiful words to

hear. I had just become a Mammy for the first time, my two babies did not survive, but I was still their Mammy and I will always love that they congratulated me. I remember them telling me how beautiful my babies were, and I knew that they meant it. They really looked at them and bereaved Mammies will tell you that we know the difference of when



someone just glances, not really seeing your baby and when someone really looks, and I know they really took in every feature of our babies.

After giving us some time alone together as a family, they came back into the room and gently took their hand and foot prints on a card. They carefully wrapped Liam and Grace in their beautiful hand knitted blankets and took the most special photos of us as a family. This level of care continued throughout our stay in hospital and the bereavement midwife gave me another of my favourite memories with Liam and Grace, the time to bath them both. It was such a lovely thing to experience with my beautiful babies and I am so grateful to have these special memories.

I cannot speak highly enough of the care we, as a family, received and I will always be grateful to the wonderful ladies who cared so lovingly for Liam and Grace.

Nina, Liam and Grace's Mammy



Cot and bed occupancy

While in hospital, bereaved parents may find themselves surrounded by sets of healthy twins who are expected to go home alive and well. Naturally, this is upsetting for bereaved parents who have lost one or both of their twins. Therefore, staff should try to separate a surviving twin from sets of living twins. If this is not possible, discuss this with the parents and forewarn them that there may be living twins on the ward or Neonatal Intensive Care Unit. Ask the parents if they would like other parents on the ward or unit to be informed, so that they are sensitive to their loss. If an alternative cot space becomes available, ask the parents if they would like to move. In addition, if one twin has died, and another baby needs to use this cot space, warn bereaved parents that this will happen beforehand.

On the antenatal ward, aim to avoid placing a pregnant mother who is anticipating the loss of her twin or twins, in a bed or ward near a pregnant mother who is expecting to deliver healthy twins. Again, if this is not possible at the time, discuss this with the mother and ask her if she would like to be moved to an alternative bed as soon as one becomes available.

If a baby or both babies are expected to die soon after delivery or who have died before delivery, respect and quiet should be given to the family and only essential staff should be present to provide care and support at every point during the families stay in hospital - antenatally, during delivery and post-natally.

Breastfeeding and antenatal classes

For parents who are anticipating a bereavement of a twin in utero or where one twin has already died in utero, it is essential that mothers be given the choice to have one-to-one breastfeeding classes and antenatal classes with a midwife rather than it being offered in a group setting, as it may be difficult for a bereaved mother at this time to chat with other mothers who have not lost a baby.

Keeping families together and providing support

Sometimes, bereaved parents and their babies need to be separated for example, a sick twin may need to be transferred to the Neonatal Intensive Care Unit with the father, while the mother remains in another part of the hospital recovering from the delivery and spending precious time with her baby who has died. Where possible, keep families together or as near as possible to each other in the hospital; bereaved parents may feel great regret if they are not given the opportunity to spend time with their baby or babies before they have passed.

By keeping babies together, this will enable parents to spend time more easily with each baby and to support each other. If it is not possible, discuss and explain this sensitively to parents.

Even after one baby has died, parents can be torn between spending precious time with their baby who has died and their surviving twin. Sometimes, parents may feel sad that they did not get the opportunity to spend more time with their twin that died because they were caring for their surviving baby. Staff can help by offering to care for the surviving baby, even for a short while, so that bereaved parents can be freed up to spend time with the baby who has died. Extended family and friends should also be facilitated to help in this way as well.

If possible, if one or both twins have died, a bereaved mother and her babies, should be cared for in a dedicated bereavement room with an ensuite toilet and shower. The dedicated bereavement room should have a double bed and / or a second single bed to give the father or other family members and friends the option to stay overnight, so that valuable memories can be created and also that families are together to support each other.



Emily and Heidi's story

When I discovered that I was pregnant with monoamniotic twins, Emily and Heidi, I was told that there was a high risk that their cords could become entangled because they were in the same sac.

I felt reassured however that all would be okay because I had regular scans. The twins grew stronger and were getting bigger and bigger and I even familiarised myself with the Neonatal Intensive Care Unit in the hospital, so that it would not be a shock to me when the girls were delivered. However, at a scan at 29 weeks, I immediately knew that there was something wrong when the doctor went quiet and got up and left the room after scanning me. Emily had died. My poor consultant had to leave the room to compose herself. To save Heidi, I had an emergency c-section.

My family and I got to spend precious time with Emily before her burial. We had a lovely ceremony in the hospital chapel. While trying to visit Heidi in the Neonatal Intensive Care Unit we were planning Emily's funeral. I did try to focus on Heidi as such as possible because she was so tiny and premature but that was really hard because I was also grieving for the loss of her twin sister and I just could not put my grief aside.

Heidi spent 9 weeks in hospital fighting infections. She thankfully made a full recovery and is now a healthy and lively 10-year-old. I am so grateful to have Heidi as well as her older sister Zoe and little brother Charlie, but we miss Emily every day and wish she were here with us. We are thankful to the doctors because we could so easily have lost both babies.

Emily is still a massive part of my life and she has inspired me to volunteer with the Irish Neonatal Health Alliance, so that I can help other

families through their journeys of prematurity and baby loss. In particular, I have become involved in their Angel Gown project where generously donated wedding and communion dresses are designed into beautiful burial gowns for babies who have died.

Sharon, Emily and Heidi's Mammy



Fears of bereaved parents

Keep parents informed of choices and supports available to them on an ongoing basis. Care plans and potential risks should be discussed with parents in detail and joint decisions should be made.

Staff should be aware that parents can sometimes begin to worry about what their twin who has died will look like, particularly if they must wait sometime before he or she is born. It is important to reassure parents that it is not likely that they will regret seeing and holding their baby after delivery. Parents can also feel anxious about their baby's upcoming funeral and worry about how they will cope caring for their surviving twin at the same time.

Bereaved parents often become anxious about the well-being of their surviving baby as well. Fear that they too may die can be become overwhelming. Staff should take time to listen to parents concerns and offer them an extra level of reassurance during the rest of their pregnancy and after the delivery.

It is important to remember that there are huge benefits if a mother can be linked to her surviving baby through a video link on a camera, if her surviving baby is in the Neonatal Intensive Care Unit. If a camera is available, ask the parents if they would like to use it.

The journey to have a family

It is vital for staff to remember that for many bereaved parents this pregnancy might have been their last chance to have children after many years of infertility. The journey of infertility in addition to the loss of a baby, can compound a parent's grief.

Bereaved parents may feel anxious about whether they want to go through the emotional rollercoaster of further fertility treatment and if they have the money to pay for it. They may also feel sad that it is unlikely that they will have the opportunity to have twins again in another pregnancy and feel a sense of loss with losing the status of being the parent of living twins.

Making memories

Staff play an active role in assisting parents to create memories with their twins. If one or both of their twins will die during pregnancy or soon after delivery, staff should try to encourage parents to make memories of their babies while they are alive as it may be their only chance to do so. Parents should be offered an ultrasound scan picture of both babies if possible.

Parents may also decide to see and hold both babies together before and after their passing. Staff should try to facilitate this to happen, if possible. Later on, parents will value this memory.

Photographs and videos often become the most treasured keepsakes of bereaved parents and their families. With the permission of bereaved parents, a staff member could offer to take photographs on behalf of the family. Consider taking photographs of the babies together and with both parents holding the twins. It is also nice to take photographs of the twin's hands touching. These photographs can be saved and offered to the parents later. Staff can also try to encourage bereaved parents to take photographs and videos themselves of activities that they carry out with their babies such as sleeping with, washing, massaging, dressing, reading stories to and singing to their twins.

Now I Lay Me Down to Sleep (NILMDTS) Ireland offers the gift of healing, hope, and honour to parents experiencing the death of a baby through the overwhelming power of remembrance portraits. Professional-level photographers volunteer their time to conduct an intimate portrait session, capturing moments parents spend with their babies. Parents are gifted with delicately retouched heirloom black and white portraits free of charge. Find out more at www.nowilaymedowntosleep.org

Féileacáin (www.feileacain.ie) provides memory boxes to maternity units throughout Ireland. In each memory box, there is a small cuddly teddy. Consider giving a teddy to each twin. If one twin has died, their

teddy can be buried with them and the surviving twin can keep their teddy as a keepsake.

Féileacáin, as part of its '*Imprints so Precious*' service, can take the handprints and footprints of both twins in the same tile of clay or place them in the same frame. This can be a treasured keepsake for many bereaved parents.

Féileacáin can also send parents the gift of a beautiful purple teddy for surviving twins and triplets, which says "for my twin sister/brother" or "for my triplet sister/brother".



Mementos

Staff can offer to assist bereaved parents with gathering keepsakes of both their babies. Keepsakes can include locks of hair, footprints and handprints, cot cards, blankets, and identification bracelets for example. They could be placed in a memory box with one for each baby or in a joint memory box.

Angel Gowns, (right) made from donated wedding and communion dresses by volunteer seamstresses in the Irish Neonatal Health Alliance and A Little Lifetime, are available in all 19 maternity units throughout the country.

Beautiful knitted blankets, hats, and cardigans have also been generously donated by volunteers to each maternity unit. Staff can show parents a selection of these items and they can choose some for their babies. Parents might consider choosing matching items for their twins to wear.





Mia and Emma's Story

To find out that we were expecting twins was very special. We were so excited.

At our 20-week scan, we found out that Mia, twin 2, had hypoplastic left heart syndrome. She died in utero at 32 weeks on the 18th March 2015 and four weeks later, our twins were delivered by c-section. Emma was born first. Mia was born one minute later.

After their delivery, Mia and Emma lay together in my room in two separate cots. We took lots of photographs of them and we tried to spend as much time as we could with them both. It was hard to find a balance between spending precious time with Mia and caring for her twin sister Emma. I struggled to mother them both equally, just like any mother of twins would. Each night, the nurses wheeled Mia down the corridor and back to the morgue to keep her cool. They then so kindly took Emma into their care, so that I could get some sleep, in advance of Mia's upcoming funeral.

On the day of Mia's funeral, she was beautifully laid out in a lace-covered Moses basket in the hospital chapel. We dressed her in a cute pink crochet cardigan, that the hospital gave to us.

We brought Mia home in a little white coffin in the back of our car, so that we could have a funeral service at home. The hospital chaplain had produced a lovely order of service booklet, so the priest used that as a guide for the service.

My time with Mia was so brief but so precious. She was with me for five days, all of which were spent in hospital, and most importantly, the hospital staff gave me the chance to mother her for those days.

Niamh, Mia and Emma's Mammy



Finding out if the babies are identical

If parents do not already know, they might like to find out if their twins are identical. A surviving twin will want to know this in the future. A member of staff should sensitively discuss testing with parents. Testing is also very important to help to find a possible cause of a twin's death and risks of it happening again.

Burial or cremation

Some bereaved parents who lose both of their twins may find comfort in their babies sharing a funeral and being buried or cremated together in the same coffin. If one twin has died and it is expected that the other baby is going to die soon as well, staff might consider suggesting to the parents that they might delay the burial or cremation, so that the twins can be buried or cremated together. However, some parents might not want to wait or discuss this because they do not want to even think about their other baby dying as well. It might also be best to postpone burial or cremation of a baby, if it is going to coincide with other important events such as surgeries for the surviving twin.

The most important thing to do is to discuss funeral options with the parents, so that they can make informed choices that are right for them.

Going home

Bereaved parents who have lost a baby in a multiple pregnancy will find going home without their baby or babies to be devastating. If bereaved parents are going home with a surviving twin, they may struggle with the experience of feeling joy and sadness at the same time. Grief that has been suppressed while the parents are in hospital often tends to surface around the time they go home, as the reality of what has happened begins to sink in.

Follow-up appointments

It is vital for staff to remember that for any follow-up appointments in the hospital, bereaved parents should not have to wait in a waiting room where there will be new-born babies and in particular new-born twins or mothers who are pregnant. Staff should take this into account when arranging appointments.

With the parents' permission, clip the butterfly alert symbol to the mother's and surviving twins medical notes so that staff involved in the parent's care after discharge are aware of the parent's loss.

What next?

If you are caring for a parent who has experienced loss in a multiple pregnancy, ask them if they would like to be linked in with support organisations listed below. Remember also that these organisations can also offer advice and support to staff as well.

- A Little Lifetime Foundation www.alittlelifetime.ie
- Anam Cara www.anamcara.ie
- Barnardos www.barnardos.ie
- Bereavement Camp for Families at Barretstown www.barretstown.org
- Féileacáin www.feileacain.ie
- Every Life Counts www.everylifecounts.ie
- Firstlight www.firstlight.ie
- Leanbh mo Chroí www.lmcsupport.ie
- Now I Lay Me Down to Sleep Ireland www.nowilaymedowntosleep.org
- Miscarriage Association of Ireland www.miscarriage.ie
- Peas in a Pod: Loss in a Multiple Pregnancy @peasinapodireland
- Potter's Syndrome www.potterssyndrome.org
- Pregnancy and Infant Loss Ireland www.pregnancyandinfantloss.ie
- Rainbows Ireland www.rainbowsireland.ie
- Soft Ireland www.softireland.com
- Twins Trust UK www.twinstrust.org/bereavement.html
- The Irish Childhood Bereavement Network www.childhoodbereavement.ie
- VP Ireland @vasapraeviasupportandawarenessIreland

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