



Baby Loss in a Multiple Pregnancy

A Guide to Coping with Grief and Loss



About this booklet.

This booklet focuses on the experiences of parents who have lost a baby or babies in a multiple pregnancy. The term 'twin' is used in the booklet but the information is also relevant to triplets and higher order multiples.



Introduction.

The experience of losing a baby is devastating. Being a bereaved parent can be lonely and isolating. Family and friends may be available to offer support but you may feel that they do not fully understand what you are going through. There are a number of support organisations available to help. You can find their contact details at the end of this booklet.

How you might be feeling.

Loss in a multiple pregnancy can bring about particular feelings. These might be:

- Loss of your special status in society as being the parent of twins.
- Sadness that you may not be acknowledged by others as the parent of twins.
- Broken-hearted, for your own loss, when you see baby twins and other women who are expecting twins.
- If you have a surviving twin, sadness about the loss of their future relationship with their twin brother or sister.
- Guilt about initial worries that you may have had about being a parent to twins.

Knowing that one or both of your babies will die.

You may have been told that one or both of your babies has a medical condition, which means that they will die during your pregnancy or soon after delivery. Although it might be difficult for you, try to think about ways of making memories of your babies right now. You might for example:

- Ask for a scan picture of both babies whenever you are having an ultrasound.
- Take photographs of your “twin” bump.
- Plan in advance which siblings, relatives and friends you would like to meet your babies.
- Buy matching items for your babies such as teddies, blankets, clothes, so that you can dress them alike when they arrive, if you choose to do so.

If you are still pregnant but one baby has died.

If you are still pregnant but one of your babies has died, you may be advised to continue with the pregnancy, so that your surviving baby can have the opportunity to develop further. You may not be able to meet your babies for a number of days or weeks. Knowing that you are carrying both life and death can be hard. You may worry about what your baby who has died will look like, particularly if you have to wait sometime before he or she is born. It is not likely however, that you will regret seeing and holding your baby. Talk to your midwife about your concerns. Your midwife could, for example, take a photograph first of your baby and support you with making a decision about seeing them.

You may also feel anxious about your baby’s upcoming funeral and worry about how you will cope caring for your surviving twin at the same time.

It is not uncommon, at this time, to start to worry about the well-being of your surviving baby. Fear that they too may also die can become overwhelming. However, your doctor and midwife will be offering you an extra level of care during the rest of your pregnancy, which can be reassuring.

Mia's Story

To be finally pregnant, and pregnant on twins, was very special.

At our 20-week scan, we found out that Mia, one of our twin girls had hypoplastic left heart syndrome. Mia died in utero at nearly 32 weeks on the 18 March 2015. She was delivered 4 weeks later, with her twin sister Emma, weighing 3 pounds 6 ounces.

When Mia and Emma were delivered, they were both beautiful and very alike. It was so important to us that we held Mia, talked to her, and took photographs of her.

Now, we visit Mia's grave regularly with Emma and Alice, Mia's older sister. They play chase around the headstones as we pot Mia's plants and cut her grass. We always light a candle on Christmas day for Mia and have decorated our Christmas tree with lots of angels and butterflies. We also do something special on their birthday to remember Mia.

I love to talk about Mia, and Alice and Emma talk about her naturally too. Sometimes I can hear Alice showing a friend the photograph of Mia that hangs in our home.

Mia will always hold a very special place in our hearts. We miss her so much and we wish that she was here with her sisters.

Written by Niamh, Mia's Mummy

Twins Mia and Emma holding hands. Sadly, Mia had passed away. This photograph was taken by Now I Lay Me Down to Sleep Ireland



When your baby is not doing well after delivery.

If your babies are born alive, one twin may be doing well but the other may not or both twins may be unwell. You may find yourself struggling to know which baby needs your care the most. If one of your twins dies and your other twin is sick, you may find that you do not start to “grieve” until your surviving baby gets well. Even after one baby has died, you can be torn between spending precious time with your twin that has died and your twin that is alive.

After delivery.

Here are some suggestions that you might like to think about when your babies have been born.

Photographs.

Photographs will be treasured keepsakes of your baby. Consider taking photographs of both babies together, both parents holding the babies, and a photo of all the immediate family together.

The funeral service.

Here are some suggestions to think about in advance of your baby’s funeral:

- You might like to place items in your baby’s coffin, such as a cuddly toy or piece of jewellery, and keep an identical one for your surviving twin.
- Consider bringing your surviving baby to some or all of the funeral service, so that you can tell them when they are older that they were involved.
- It might be comforting for you to recognise that your babies are twins, at the funeral service, by mentioning it in a poem or dressing them alike, for example.
- If both twins have died at the same time, you might like to ask if they can be buried together in the same coffin.

Finding out if your twins are identical.

If you do not already know, you might consider finding out if your twins are identical. If you have a surviving twin, they may want to know this in the future. This information is very important to their sense of self. A member of staff should sensitively discuss testing with you.

Ethan's Story

We found out at our 12 week scan that we were expecting identical twins. My babies grew side by side for 36 weeks. It was a wonderful time full of excitement and planning to get our home ready for the babies. My pregnancy went well until one day I suddenly developed swelling in my left leg and across my bump. I was admitted to hospital. Two days later on the 11th September 2015 our beautiful baby boys were born by caesarean section.

Completely unexpectedly both babies were flat at birth. The doctors tried to save Ethan but it was too late. He had died.

It was the most helpless moment of my life. After being told an hour before theatre that both babies were perfect, we were left completely devastated. We held both our babies together for a short time.

Having to say goodbye before we got to say hello was heartbreaking - our lives changed forever. Andrew was transferred to NICU but when I saw him in his incubator all alone, I felt so heartbroken for him. He had been robbed of such a unique bond.

Dealing with the shock of this cruel loss and trying to organise a funeral and a homecoming was the hardest thing we have ever had to do.

There are many people who still talk about Ethan and remember that he was Andrew's twin brother. We celebrate their birthday each year with family. My heart aches on milestones which they should be reaching together hand in hand. Now, a few years on since Ethan's passing, I feel we simply had less time with him but not less love for him. Ethan will always be part of our lives, even though it isn't the way we wanted it to be.

I will be forever grateful for being a twin mammy.

Written by Barbara, Ethan's Mammy



Butterfly alert symbol.

Sometimes, while in hospital, staff and visitors may not know that your surviving baby is a twin. To address this, the *Irish Neonatal Health Alliance* launched the Butterfly alert symbol and accompanying poster, which has been sent to all 19 maternity hospitals in Ireland. This symbol indicates that a baby, on whose cot it is displayed, is the survivor of a multiple pregnancy. Healthcare staff can also download the symbol from the Irish Neonatal Health Alliance website at: www.inha.ie/family-info/



Bringing your surviving twin home.

Caring for a new baby is exhausting, emotionally and physically, at the best of times. This can be made more difficult, if you have the additional stress of coping with grief for your baby who has died. Celebrating one twin's life and grieving for the other at the same time is very challenging. Here are some of the feelings that you might have:

- Scared that something awful may happen to your surviving baby. This fear is normal after the trauma of losing a baby. Talk with your doctor to relieve any fears that you might have.
- Distressed that others may think that you are okay because 'you have another baby'. But in reality, your surviving twin will not replace the twin that you have lost.
- Upset that some people do not mention your baby who has died and only focus on your surviving twin.
- Struggling to find a balance between caring for your new baby while at the same time spending time with your baby who has died. You may feel sad that you did not get the opportunity to spend more time with your twin that died because you were caring for their surviving brother or sister.
- Feeling "robbed" of the happiness parents should feel when they have a new baby. You may be very happy to have a new baby but at the same time totally devastated that your other baby has died.

When you go home from the hospital, you may find yourself thinking about the baby who has died almost constantly but functioning as best you can for your surviving twin. Do speak to your doctor or public health nurse if you think you are struggling to cope.

Aidan and Donnacha's Story

Aidan and Donnacha were due on 26 January.

After 23 weeks of a seemingly easy pregnancy and without any warning Aidan arrived first on 30 September, perfect on the outside but just too early for his little brain to be strong enough. He left this world on 1 October.

Illness, infection and threatened septicaemia forced me to be induced on 2 October. Donnacha arrived then a little stronger than Aidan, he even managed a little squawk when being born. All of a sudden we had one twin who had died and another fighting for his little life.

The fight became too much for Donnacha and he joined his twin brother on 5 October taking with him all his Mam and Dad's hopes and dreams.

Both too perfect for this world.

Written by Ellie, Aidan and Donnacha's Mummy



Cards and gifts.

If you have a surviving baby, it is likely that you will receive both congratulations and sympathy cards at the same time.

You may find it upsetting if you only receive a congratulations card for your surviving baby. If you know that friends and relatives are going to send you a card or gift, you or a family member may also like to ask them to remember your baby who has died by mentioning their name on the card or

through the gift that they choose. You might also find it helpful to send thank you cards, which acknowledges your loss and your joy.



Headstone wording.

On your baby's headstone you may like to acknowledge the fact that your baby is a twin. If you have a surviving baby, you might consider writing '*Twin to ...*' and if you have other children '*Younger sister to ... and twin to ...*'. If both babies have died, the following wording for example could be used - '*Together forever*'.

Coping with special days and milestones.

If you have a surviving twin, it can be difficult to get the right balance between celebrating one child's special day, while remembering the other. Special days such as birthdays and first day at pre-school may now be tinged with both happiness and sadness. You might like to allocate time during the day to remember the child who has died or you might hold a separate Remembrance Day for them a few days apart, perhaps their funeral date.

You could also ask a family member or close friend to help you with the celebrations, in case you need some time out by yourself if you suddenly feel sad.

On birthdays and anniversaries, children, especially surviving twins, often need to talk about their brother or sister who has died and be reassured that they have not been forgotten. You could remember your baby with your children by visiting your baby's grave or lighting a candle for them.

Another example is to place a symbol such as a butterfly, star, angel or feather on your surviving twin's cake.

Niamh's Story

Early in 1990, after fertility treatment, I was pregnant with twins. I was 34 at the time. Shane and Niamh were born in November, a little more than eight weeks early. Their birth weights were 3lbs 11ozs and 3lb 8ozs.

Shane was born first and although he was small, his lungs were fully developed. Niamh was breech at birth, so she had a difficulty delivery. Her lungs were not fully developed. This meant that she was on a respirator immediately after her birth. On day 2 of her life, Niamh had several brain haemorrhages ultimately resulting in her death. I held her hand during that time, which was extremely difficult and I found those last few moments until her little heart stopped beating to be harrowing.

Niamh is buried in our family plot not far from our home, which is important to me. The staff in the hospital were brilliant at the time but a referral system was not in place. A support group would have been invaluable. I needed help and at the time I really didn't know where to turn. I felt extremely alone in my grief for a long time.

I sometimes wonder what it would have been like to have a daughter. I find myself trying to picture her and what she might have looked like.

Shane is now 28 and is the light of our lives. I am not sure how Niamh's death has affected Shane as we have never discussed it in any great detail. We now have a beautiful Grandson Luke, who brings us so much happiness.

Written by Judy, Niamh's Mammy

Losing the twin parenting experience.

You may find yourself wondering what it would have been like if your twins had survived - bathing, feeding and changing two babies. You were going to be part of a special club, where you would find information about caring for two babies. But now that one or both of your twins has died, you may feel saddened that you are no longer going to be part of this club and that you are instead part of a different club - a club of parents who have lost a baby.

You may find yourself wishing that your twins were alive when you see baby twins. You will meet living twins in so many places that you go. For example, you may have gone back to work to find out that another woman in your office is expecting twins; you may go to playschool with your other children to find out that there are twins in their class and you may come across double buggies when out and about. You will probably feel the need to look and see if there are twins in the buggy and if there are, whether they are the same combination as you have - two girls, two boys or one of each.

Talking to your surviving twin.

As they get older, your surviving twin will want to know about their twin sister or brother. It is best to talk to them about what has happened from an early age, so that he or she will feel able to talk naturally about their twin and feel free to ask questions. Try to answer any questions honestly using age-appropriate language.

You may also like to display mementos around your home, so that your surviving child can feel that their twin is still part of the family. You could read stories about twins and tell them that they are a twin. A good children's book that might be helpful is *Always My Twin* by Valerie Samuels, *I'll Always Be a Premmie Twin* by Nicki Cooper (www.blurb.co.uk), *Two Little Monkeys* by Kimberly Jackson (www.lulu.com) or you can purchase 'The Story Of...' books for families who have lost one or both twins (www.personalisedchildlossbook.com/sam-and-finn/).

Twins Portia and Charlotte, both of whom passed away just before birth.



Twins Andrew and Ethan in utero. Unfortunately Ethan could not stay.



You may be concerned about how much your surviving child will be affected by the loss of their twin. Some children may think that they are to blame for their twin brother or sisters passing and feel guilty that they could not prevent them from dying. It's important to reassure your child that it's not their fault. Surviving twins may also try to make up for their loss by trying to 'live for two'. You could tell your surviving child that although they will miss their twin brother or sister in their lives, they are valued too as individuals in their own right.

Future pregnancies.

If your twins were conceived using fertility treatment or if you are an older mammy, you may feel that time is slipping by and that you want to start trying for another baby sooner than later. If you have had previous fertility treatment, you may worry about whether you are emotionally strong enough to cope with the possibility of not conceiving at all or for some time.


You may also question whether you are able to go through the emotional rollercoaster of fertility treatment again and have money to pay for it.

You may feel sad that it is unlikely that you will have the opportunity to have twins again in another pregnancy. If you become pregnant again on one baby, it's not uncommon to feel that the scan looks "lonely".

Advice for family and friends.

Bereaved parents continue to grieve for many years. Continue to ask them if they are okay, particularly on special days such as their twins' birthday and anniversaries.

If parents have a surviving twin, all of his or her first milestones will remind them of their loss such as first day at school, graduation and wedding. Parents will appreciate your kindness and support on these days and the lead up to them. Say their baby's name, include them in conversation and remember them.



Triplets Zoe, Anna and Corina.
Sadly, Zoe and Anna were born silently.

Portia and Charlotte's Story

In August 2014, I found out that I was pregnant. We held our breath until I had my first scan at which we were told the amazing news that there were two heartbeats. For the rest of my pregnancy, we held our breaths. At one stage, Charlotte started measuring a little smaller than her sister Portia but both of them were always very active.

As Charlotte was a bit smaller at that time, I felt more protective of her. I thought that she might be the one who would be lagging behind her twin sister in terms of confidence. I pictured Portia barging into a party, going straight to the centre of the action, while Charlotte followed a few steps behind. But we never got to know Portia and Charlotte beyond their happy little kicks. We never got to see the colour of their eyes or to hear their voices. Portia and Charlotte never got their future.

On 17 March 2015, their little hearts stopped beating. It seems that the cause was acute twin to twin transfusion syndrome, a condition that is unpredictable, undetectable and altogether catastrophic.

But I do know that I delivered two of the most beautiful sleeping princesses, ever so silently, shortly before and after 3pm on 19 March 2015. I am truly honoured that I got the opportunity to bring their sleeping selves into this world and to hold them while their little bodies were still warm from being inside me. I know that none of this is my fault but I am their mother, my job was to love them and to mind them. And while I could not and cannot mind them, I will always love them. We are irreparably broken.

Yet there are aspects of our loss that are different. It took me a while to work out what, for me, was the difference. It hit me when I recalled a story that a very dear friend who is herself the mother of twins told me while I was pregnant with Portia and Charlotte. She showed me a gorgeous photograph of her boys on one of those big rope swings and it looked like they were sleeping while wrapped up in each other's arms. I asked her if they were asleep and she said that they weren't, that they were just having some time out together; that it was a "twin thing".

I now know that this is what I am grieving for on top of our loss. I am grieving for the "twin thing" that I will never get to see our girls share. I know that they have their "twin thing" but what makes me feel so hard done by is that they are not having their "twin thing" here with us.

Written by Claire, Portia and Charlotte's Mummy



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What next?

If you or someone you know, if affected by the death of a baby, there is help available. The following is a list of some the organisations that can offer advice and support:

- 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
- Firstlight - www.firstlight.ie
- Leanbh mo Chroí - www.lmcsupport.ie
- Now I Lay Me Down to Sleep - www.nowilaymedowntosleep.org
- Miscarriage Association of Ireland - www.miscarriage.ie
- Potter's Syndrome - www.potterssyndrome.org
- Rainbows Ireland - www.rainbowsireland.ie
- Soft Ireland - www.softireland.com
- Tamba UK Bereavement Group - www.tamba.org.uk/bereavement
- The Irish Childhood Bereavement Network - www.childhoodbereavement.ie
- VP Ireland - Find us on Facebook at **Vasa Praevia Support & Awareness Ireland**.

Your notes:

A series of 25 horizontal dotted lines for taking notes.



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