

A Guide to Coping with Grief and Loss





# The death of your baby is a huge bereavement for you and your family.

Initially, you may feel numb and shocked and find it hard to take on board what has happened. You may feel that you will never be happy again and experience deep, deep sadness. You may wonder "why" this has happened to you and want to talk over what has happened, again and again. You may feel that "you are losing your mind" and have a lot of anxiety and irritability. You may also experience forgetfulness, a lack of strength to make decisions and feel the need to withdraw from society - for a while at least.

The physical reactions to your baby's death may include feeling weak and nauseous, having diarrhoea and experiencing a feeling of heaviness in your body. You may lose your appetite or start to comfort eat. You may be unable to sleep. You may long to hold your baby again and feel "empty" arms.

All these reactions are normal. However, if you feel that you are not coping, talk to your local family doctor. You can also contact the support organisations listed in this booklet for support and advice.

### Remembering our Son

In May 2014, we lost our perfectly healthy only son Conor so unexpectedly due to complications of undiagnosed vasa praevia. Our handsome little man was born 9 days overdue but he needed extensive resuscitation. Conor sadly gave up his fight when he was only 17-and-a-half hours old.

He grew his wings and left us all too soon on a Wednesday morning.

Conor knew nothing but love from all who helped care for him during his short time with us. I too became very unwell and it took 12 days before we could all come home together as a family.

It was extremely important to us that Conor would come home before leaving us forever in a physical presence. We wanted everyone, from family to friends, to get an opportunity to meet our beautiful boy who touched our lives so fleetingly and for him to know how loved he was. Those days are etched in our minds forever, every little detail. Our lives changed forever.

We spent those initial first months in a fog of utter devastation, shock and anger that Conor had died. We had to advocate for an inquest to be held along with an external review to ensure national learning and improvements in care happened and would be implemented. They were very difficult processes to deal with and slow and draining on a family's wellbeing and freedom to grieve properly but I made a choice then to raise awareness about vasa praevia and I will continue to campaign for changes in policy of screening to try to save other precious little lives. This focus has been my saving grace as well as meeting other families on this journey.

We celebrate Conor's birthday every year. Santa always leaves a little something for him under our Christmas tree.

He is included in all we do as a family. We light his candle every day.

I talk to Conor all the time. Playing music is therapeutic for me.

There are certain songs that are my special bond with Conor and they help me to release my emotions. Talking about our little man openly helped me a lot. I found finding a good listener helped me too.

I only visit his grave on a weekly basis now as I know he is with me always no matter where we roam. Most family and friends remember Conor always and express their love openly for our lost wonder child.

If it weren't for the support of the pregnancy loss charities, I don't know how we would have survived.

There is hope after the darkness.

Written by Siobhan, Conor's Mammy

#### Seeing and holding your baby.

You may feel anxious about seeing your baby after he or she has passed away, in case you may be overcome by your emotions. But most parents do not regret seeing and spending time with their baby. Talk to your midwife about any concerns that you have, so that they can talk through your fears with you.

#### Spending precious time with your baby.

The hospital can provide you with a cuddle cot, which looks like a moses basket with a cooling unit, so that you can spend as much time as possible in hospital with your baby.

You might like to think about what activities you would have done with your baby if he or she were alive. It may be comforting to carry out these activities. They might include holding, sleeping with, washing, massaging, dressing, reading stories to and singing to your baby. You could request assistance from hospital staff and family members/friends could also join in.

Your baby's brothers and sisters, grandparents, aunts and uncles might also like to spend time with your baby. Think about who you might like to invite to meet him or her.

Consider keeping a daily journal which records all of the activities you do with your baby. It will be a lovely keepsake. Take time to examine all of your baby's features too. Look at their hair, feet, nails and hands and write down their weight and height.

Féileacáin's *Precious Prints* service will take your baby's hand and foot prints and in a few weeks' time, you will receive a beautiful framed clay mould of their hands and feet. Ask your midwife for more information about this service.

#### Taking photographs and making videos.

Think about taking photographs of your baby. If you are not sure that you want photographs, hospital staff can take some and keep them for you, so that you can ask for them later when you are ready. You might also like to take videos of you and your family with your baby.

#### Memory boxes.

Hospital staff will give you a Féileacáin "Remembering" memory box, which contains a number of items that will assist you to make memories of your baby. You can also fill your memory box with a number of keepsakes such as a lock of your baby's hair, toys that your baby held, their identification bracelet, cot card, clothes, blankets and cards that you received.

## Bobby's Story

Bobby Fortune was a much wanted second child and our journey to have him was incredibly difficult. We had been blessed when our clever, kind and gorgeous red-headed daughter Lily arrived in 2012. During 2014 and 2015 there were heartbeats, then they were gone and we grieved for them. To prevent further loss, we went through IVF with implantation screening and we became pregnant again on Bobby. The shock to hear something was wrong with him was enormous.

Bobby was diagnosed with a life-threatening problem called a Congenital Diaphragmatic Hernia on 1st March 2016 at his 21-week scan and was given a 50/50 chance of survival. Following his diagnosis, we

went on a 14-week rollercoaster during which time he showed us his fighting spirit. There were times we thought we might lose him and even moved our lives to Belgium for in utero surgery, which sadly was not meant to be. Unfortunately, Bobby came early at 34 weeks 2 days and passed away 7 hours later in my arms. Sadly, his lungs did not match his incredible spirit. It's been an extremely bumpy ride, one I didn't think I'd personally survive and one we are still on.

The second and third years after loss, have been the hardest for me and seeing a bereavement counsellor has been simply lifesaving. Relationships have changed in both positive and sad ways; there have been some losses along the way. I'm coming to terms with the fact that baby loss is not something you can truly understand unless you have been through it.

Sometimes I feel like a large Lego set slowly being

rebuilt by a 3-year-old. The future still remains a little vague but there is also great joy amongst the sadness. You learn to live again and there is no choice when you have an existing child to love. Losing Bobby changed me as a person and I lost a part of myself when he died. I also learnt a lot from my son and have made positive changes in my life I once feared.

Grief is messy, unpredictable, harrowing and life changing. It will always be there and I even bring it with me in my suitcase on holidays. I will miss Bobby for the rest of my life. Grief is the price you pay for love.

Written by Emma, Bobby's Mammy



#### Deciding on a funeral.

You will need to make decisions about your baby's funeral. A funeral can be religious or non-religious. It can be a large or small service. It can be in your own home, at your local church or at the hospital.

You will also need to decide about whether you will bury or cremate your baby. If you choose to bury your baby, you will need to make a decision about which graveyard he or she will be buried in.

You might also like to wrap your baby in a special blanket and clothing for their funeral. Angel Gowns, 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 Irish maternity hospitals. Beautiful knitted blankets, hats, and cardigans have also been generously donated by volunteers to maternity hospitals. Your midwife and chaplain can show you a selection of these items and you can choose some for your baby.

Think about what special items you might like to place into your baby's coffin such as a photograph of you, a letter or a cuddly toy. If you decide to cremate your baby, there are regulations about what you can place in the coffin. You can ask the crematorium for more advice. Remember also, if you choose cremation, there may not be any ashes. Do keep this in mind when making a decision.

Take your time to think about what is right for you. Your midwife and hospital chaplain will talk you through all of these options.

#### Going home.

The hospital will inform your local public health nurse that you have left hospital. The public health nurse will be in contact, so that they can offer you further care at home.

If you would like to bring your baby home for a short while, Féileacáin, whose contact details are listed in this booklet, provides community *cuddle cots* for this purpose. Your midwife can discuss this with you further or you can contact them directly yourself.

If you have recently given birth, your milk may come in or you may have been pumping milk for your baby. You can talk to the public health nurse about ways to suppress your milk or ways to donate it.

You may also have painful stitches and the normal post-natal blues a few days after your baby's birth. Give yourself time to recover. Ensure that you attend your six-week post-natal check-up. You may prefer to have the check-up in your local family doctor's clinic rather than returning to the hospital where your baby died.

#### Coping with your loss.

At first you may feel consumed by grief. Some days will be worse than others. You may feel exhausted all of the time and find it very difficult to function. Think about accepting practical help from family and friends. They could bring you ready-made food, carry out everyday household tasks, do some grocery shopping or mind your other children.

Meeting people may be difficult for you right now, as you may find yourself having to tell them that your baby died. If you have other children, it may also be difficult meeting other parents at the school gates. If possible, ask for help to drop off and pick up your children until you feel more able to cope. It is okay to stay at home and withdraw for a while.

Your grief may also be triggered by certain events and dates such as your baby's due date, Mother's Day, Father's Day, festivities and family celebrations. Try to have supports available from family and friends around these times. It might also help to get in touch with support organisations listed in this booklet, so that you can talk with others who have been through similar experiences.

#### Family and friends.

Family and friends will also experience grief. They may not talk about your baby in case they upset you. You might consider telling them that it's okay to talk about your baby and you want to talk about him or her. Think about getting in touch with friends or family members who will listen and support you.



### Our First Baby, Conor

I'm the mother of a beautiful little boy Conor who was stillborn in the summer of 2014. Conor was our first baby. We had experienced an early miscarriage beforehand and so had taken nothing for granted during the pregnancy. I started to become anxious when we reached 40 weeks. We were told all was perfect with our baby and were booked in for a caesarean section. Two nights before the section the two of us went to sleep but only one of us woke up. I quickly noticed the absence of a "good morning Mummy" kick. After eating breakfast, we made that fateful trip into the maternity hospital. No heartbeat could be found...Conor had died. I went into shock.

We returned home broken and arrived back to the hospital two days later terrified of what lay ahead of us. I delivered Conor naturally and silently into the world. I didn't know if I wanted to hold him but once I saw him, I fell in love. He was and is my son. We held a small remembrance service in the hospital with family and our closest friends.

The following weeks and months were the hardest. As the shock lifted the trauma of what had happened hit and so did an immense sense of loss; loss of my son and loss of me too. Attending support groups and meeting other mums kept me going. Four years on I miss Conor as much as ever but my grief has changed. I am learning to accept my new life and have found joy once more. This is something I thought would never happen. Conor made me a mother and I will never stop loving him. When asked if I have children he is always mentioned. I tell people all about the little boy who didn't get to come home.

We find ways to honour his little life and his name has been written on beaches all over the world.

Written by Imogen, Conor's Mammy

#### Talking to your children.

You may be unsure about how to talk to your children about their baby brother's or sister's death. It is possibly best to explain that the baby has died, using age appropriate language, otherwise, your children might be wondering what happened to the baby. Think about bringing even young children into the hospital to see their baby brother or sister, so that you can tell them later on that they met them.

It's also okay to cry in front of your children. Explain to them that you are sad because the baby has died.

You might consider buying a children's book about baby loss to help you talk to your children about death and loss. The support organisations listed below will also be able to offer you advice and support.

#### What next?

Throughout this difficult time, it is important that you get the support and help you need. Here are a list of support organisations and their contact details.

- 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
- The Irish Childhood Bereavement Network www.childhoodbereavement.ie
- VP Ireland Find us on Facebook at Vasa Praevia Support & Awareness Ireland.

Your notes:






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