



## What you can do

Allow the whānau to cry as much as they need, and give them time, as this shows them you are aware of their distress and that “it is okay to cry”. By letting them be sad and joining them in the pain, instead of trying to cheer them up or make it better, you are acknowledging the huge heartbreak. The early days are not a time to give advice; it might make them feel misunderstood instead of supported. It is a time to sit with them in pain. All they need is to be heard and silence sometimes works best - it is better than saying the wrong thing.

## Helpful phrases for distressed families

Always refer to baby by their name, never say “it”.

- “I am so sorry that (name) died.”
- “Take your time.”
- “If you want a hug or some other touch, I’m here.”
- “What would you find helpful right now?”
- If giving them a tissue: “I’m giving you this not so you stop crying, but so you can feel comfortable crying as long as you need to.”
- If the baby is in the room with them, and parents are holding her, you can say “(name) is so beautiful”.

## What NOT to say

- It’s not about you. It’s not about your pain and grief – even though you might be feeling grief and shock as well.
- No platitudes: these statements actually dismiss or belittle parents’ thoughts and feelings.
- There is no “bright side” – there is no “at least” e.g - “At least you have another kid”, “at least you didn’t bond with her yet”.
- Be careful with religion. Don’t say things like “God does not give you more than you can bear”.
- Be careful of euphemisms, they can feel dismissive, avoidant, and vastly underestimate their heartache. Only the actual words death, dying, and died may suffice.

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## Help families create memories

Suggest/support to, but with no pressure:

- Take photos and videos.
- Have handprints and footprints done.
- Dress baby in special clothes.
- Bath baby.
- Cut a lock of hair.
- Take baby to a significant or special place.

## Practical things you can do

- Make sure they have privacy.
- Make sure their seating is comfortable, consider the temperature and ventilation within the room.
- If you know the parent well enough, touch may be helpful e.g. reaching out a hand at some point, palm up and half-way.
- Offer to get them a glass of water or a hot drink.
- Make sure they can travel home safely if they are an outpatient, or that they have sufficient support on a ward if they are an inpatient.
- Consider whether a referral to a colleague would be helpful (e.g. pastoral care, social work, volunteer service).

## Later on, encourage parents to:

- Collect the things that remind them of their baby, like ultrasound pictures, a lock of hair, a hospital bracelet, photos, clothes, blankets or toys and put them in a special box or scrapbook.
- Write thoughts and feelings in a journal, or write letters or poems to baby. Tell baby how they feel and how much they miss them. Or paint a picture for baby.
- Plant a tree or a small garden in honour of their baby.
- Have a piece of jewellery made with baby’s initials or their birthstone.

www.sands.org.nz

www.vca.co.nz

https://wheturangitia.services.govt.nz

www.babyloss.co.nz

www.miscarriagematters.org.nz

www.hqsc.govt.nz



## Baby loss

Sadly 604 babies from 20 weeks of pregnancy, until 27 days of age, died in 2018 according to the most recent data available from Statistics NZ. This means that ten babies died for every 1000 registered births. Furthermore, it is estimated that between 13,000 to 15,000 women experience a miscarriage per year; this figure is roughly based on the statistic of one in four pregnancies ending in miscarriage. (\*14th PMMRC report).

For these families, there are no words for the magnitude of this loss and the grief and pain they will experience after this life changing event. This resource is meant to give you some information to help you support grieving parents with their loss.

### Supporting parents through grief

There is no ‘normal’ or expected length of time to grieve.

Each person grieves in a different way and for a different time - in case of the loss of a baby the grief might last a lifetime. When a baby dies, sometimes the hope of being a parent dies, too. And always life will never be the same for these parents.

Grief is individual, there is no pattern that ‘should’ be followed. Just because a baby is small physically does not mean the grief will not be little or minimal as well.

Parents may find it hard to believe that their baby died. They may want to shout or scream or cry. They may want to blame someone. Or they may want to hide under the covers and never come out. At times, their feelings may seem to them more than they can handle.

By being mindfully present with parents, gently inviting them to tell you about their baby and their experiences, and by listening without judgment, you are providing critical support. By witnessing and affirming the depth of their pain, you’re holding a safe space for their emotions. By being comfortable with their discomfort, you are demonstrating that they and their experiences are normal and acceptable, and that maybe everything will be okay, some day.



## PADA

Perinatal Anxiety and Depression Aotearoa is the national organisation committed to eliminating the stigma around perinatal mental health in Aotearoa New Zealand. We do this by championing awareness and facilitating best practice in perinatal mental health and wellbeing to ensure all families/whānau have access to appropriate information and support.

This resource was developed by PADA educator, Liora Noy based on her learnings from Vicki Culling at VCA and Sands NZ.

Sands NZ is a parent run nationwide charity supporting parents, families and whānau who have experienced the death of a baby at any age or gestation period.

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## Common feelings for parents losing a baby

- Shock
- Questioning – How? Why? Why me? What’s wrong with my body?
- Potential self-blame – What did I do wrong? How could I not protect my baby?
- In case of a still birth – cruel reversal, expected birth is now a shocking death
- Disbelief
- Trauma/PTSD/Flashbacks
- Anger
- Guilt
- Social withdrawal – from the antenatal group, work, friends who have babies
- Loss of meaning and purpose
- No more naivety/optimism – instead, the knowledge that bad things happen to good people, and babies can die
- Anxiety about future pregnancies and if it will happen again
- Hypervigilance with existing siblings and children born after the baby who died

By simply accompanying a parent (even fleetingly or temporarily) on their journey, you bolster positive thoughts, such as, “I’m not alone,” and “This is terrible, but I will survive.”



Remember that mum is also facing physical recovery after the loss – she might be bleeding, in pain and her breasts might be filling with milk if baby died after 14 weeks of pregnancy. These can be so hard to bear for some women when there is no live baby to take care for, and are a constant reminder of the loss and recent trauma.

## Partners and whānau are also grieving

A mum may have bonded with her baby during pregnancy. Her baby is very real to her and she may feel a strong attachment. The baby may seem less real to the partner, though they may have become more attached to baby later in pregnancy, when they feel them kick or see the baby on an ultrasound.

People grieve differently, depending on who they are as people and their experiences of grief around them growing up. Whether there is a mum and dad, mum and mum or dad and dad – their grief will be a reflection of them as people, as parents. There are societal generalisations made about how men and women grieve (that women tend to be more emotive and men tend to be stoic and tough) but they are stereotypes that are not always helpful when we, as professionals, are supporting bereaved parents.

The best we can do is reassure the parents that what they are feeling is a natural expression of love. And that they will experience some gendered responses out in the world – men/dads might get asked about partners rather than how they are doing themselves; women might be expected to express their feelings more openly and connect with others (in support meetings, for example). But there are no right or wrong ways to grieve the loss of a precious baby, and that’s an important message to convey.

## There’s no right or wrong way to grieve

Showing grief doesn’t have any rules or instructions - people may show their pain in different ways. But there’s really no right or wrong way to grieve or share their feelings. It’s okay to show pain in different ways. Be patient and caring with them. Encourage them to talk to each other about their thoughts and feelings and how they want to remember their baby.

“I would describe being a same sex couple experiencing baby loss as being in a small pond, within a small pond.” - The Legacy of Leo -

<https://thelegacyofleo.com/lgbt-baby-loss/>

## Sands NZ Three Point Model of Care

Sands NZ is a parent run, not for profit, nationwide group supporting families who have experienced the death of a baby.

### Slow down

There is no need to rush. In the case of stillbirth, once baby is born things can slow down, the post-mortem does not usually have to happen immediately, and the family can spend some time with their baby. Many parents have reported feeling a sense of urgency once their baby was born and a need to make decisions quickly. As a result, parents and whānau make decisions that have a lifelong impact - they don’t want to see their baby, they don’t want to bath their baby, they don’t want a lock of hair, they don’t want their other children to see this baby.

This can also be the case with a neonatal death. Sands encourages health professionals that are supporting and working with a bereaved family to gently provide as much information as possible in order for the family to make an informed decision, to give them space and time, and then gently ask again at some point if they would like to see their baby or create memories. Slowing down means the next two points are able to happen more easily.

### Assist in active parenting

Even though their baby has died, the parents and whānau are still caring for this precious member of their family. Making decisions, showing love in physical, emotional, spiritual and social ways, caring for the child – these are the ways they parent their children. Because things have slowed down, the opportunity to parent their deceased baby is enhanced. Parents, families and whānau have the time to think about their decisions – the name of their baby, whether they will have a funeral, who they will invite to see their child, what they will dress their baby in... what will happen next. The more we can encourage the whānau to actively parent their baby, the better the opportunity to create memories.

### Help to create memories

In actively parenting their baby, memories are created. The time available for parents, families and whānau to physically spend with their baby is now finite. At this point families are encouraged to do as much as possible (under the circumstances). These memories can sustain a family when things seem very bleak. Do not underestimate their importance.

E tūtaki ana ngā kapua o te rangi, kei runga,  
kei runga te Mangoroa e kōpae pū ana.  
The clouds in the sky close over,  
but above them spreads the milky way.

## Practicalities

As a health professional it is helpful to know about the practicalities of perinatal death. Most bereaved parents are in shock. They will look to you to know these things.

Knowing what baby might look like and being able to **tell parents what to expect** (the colour or state of the skin, the appearance of a baby with a certain condition).

**Taking baby home** – have a Sands ‘Transportation of a Deceased Baby’ pamphlet available.

Organising a **funeral/service** – giving parents as much information as possible.

**Keeping baby cold** – the logistics in doing this (using a Cuddle Cot if available, ice, and refrigeration if not), warming a blanket when people want to hold baby.

Knowing about the **physiological changes**, and that a deceased baby can still be held.

The **postnatal experience** for a second or third trimester loss, six week check, midwife visits, appointment with the hospital to receive the post-mortem results.

Have **resources** on hand.

Knowing that an **autopsy** and/or tests may need to be performed in order to try to obtain answers. A family does not have to have a post-mortem or autopsy performed – the choice is theirs. It maybe be helpful for them to talk about it with you.

Knowing that if a baby **died at home** there is no longer a choice, and the case is transferred automatically to the coroner.