

Saying Goodbye To Your Baby

Kindly written by Vivienne Kang, Mum to Jin, a beautiful boy who brought joy into this world in 2021.

There are no words to describe the utter devastation of having to say goodbye to your baby, leaving the hospital with empty arms, and facing the void you are left with after such tragic loss.

After what may have been days, weeks, or even months into your NICU/SCBU journey, you've had to say goodbye to your precious baby and thinking about what to do next can feel completely overwhelming.

We are deeply sorry for your loss. And, whilst this was never the way you imagined your life going, we hope that the information on this page will help you through this new chapter.

"There is a sacredness in tears. They are not the mark of weakness, but of power. They speak more eloquently than ten thousand tongues. They are the messengers of overwhelming grief, of deep contrition, and of unspeakable love."

- Washington Irving

THE DAY OF...

Rest assured that the NICU/SCBU team will support and guide you on the day of your baby's passing. And, if you have had the opportunity to put together an advance care plan, they will ensure the plan is followed and that your loved ones are contacted so that you can wholeheartedly spend these last, precious moments with your baby. The hospital team should be able to provide or arrange the following (based on availability):

› Lasting memory creation

- *Print-worthy photos of you and your loved ones with your baby that you can cherish forever www.heartfelt.org.au*
- *Hand and footprint kit*
- *Hand and foot castings*
- *Huggable Hearts*

› An ear to listen or a shoulder to cry on - each unit will have someone dedicated to this, for example:

- *Family Liaison*
- *Family Support Counsellor*
- *Consultant*
- *Palliative care team*
- *A hospital chaplain - You don't have to be religious to talk to a hospital chaplain. Chaplains respect a person's individual beliefs and will support people of any faith, or of no faith.*

› A private, quiet room to grieve and spend time with your baby and loved ones

› Swaddles and baby clothes to dress your baby in

› Arrangements to take your baby home (if this is your wish), including blankets and a protective carrying basket

› Funeral services guidance



› Support resources

- *"Beyond Words - Grieving when your child has died"* - A handbook offering a vast amount of useful information about grief and trauma, support options, and personal stories of life after loss for when/if you're ready to read them
- *"What's Happened to Baby?"* - A book offered to families with other young children who may have questions about their sibling's passing
- www.jaymacsjourney.com - a beautiful resource lovingly curated by Jay's parents, Sarah and Andrew
- Local SANDS group information
- Wheturangati

THE DAYS, WEEKS, MONTHS FOLLOWING

Every parent's grief is unique; there is no right or wrong way on how you journey through all the changes. We hope the following information and resources will give you support, choices, and comfort in knowing that you're not alone:

The Funeral

Planning a funeral service for your baby can be painful and distressing, so take your time to think about how you would like to say goodbye to your baby. You may choose to have a burial or cremation, a religious or non-religious service, or a ceremony of your own design. What's important is that you create something that is meaningful to you and your family. Below are some ideas for consideration:

- *Have a theme to personalise the experience (e.g. have people wear a specific colour and/or decorate with that colour using balloons and flowers)*
- *Memorial slideshow (e.g. gather all of your favourite photos and videos and create a slideshow)*
- *Send your baby off with meaningful tokens of love (e.g. a stuffed animal, toy, letter, poem, any other keepsake)*
- *Release a butterfly, balloon, floating lantern, etc.*
- *Plant a tree, flowers, or other plant. A tree can be symbolic to your baby's life and legacy that will continue to grow after they are gone.*

Lactation After Loss

The following guide is taken directly from *Empty Arms Bereavement Support* (pamphlet published in 2018)

Your first days and weeks at home without your baby in your arms will be extremely difficult. One of the most challenging times for many bereaved mothers is when their milk comes in. Some bereaved mothers find that the presence of milk is upsetting and want to eliminate it as quickly as possible, while other mothers find the milk to be a comforting reminder of their body's ability to care for the baby they so love and had wished to care for. There is no right or wrong way to feel and it is your choice to follow whatever path feels best for you.

How you can help your body to stop making milk

As long as your breasts sense a "demand" for milk, they will keep making it. If there is no demand, they will gradually stop.

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If you have been expressing for or nursing your baby before they passed away, you should continue to express periodically to help your body adjust to the decreased demand and avoid engorgement, plugged ducts, and mastitis.

You can adjust your schedule so that, over time, you express less and less. For example, if you have been expressing 6 times in 24 hours, drop to 5 times for a few days and then to 4. You can continue this process until you are no longer expressing at all.

When your breasts feel painful from the pressure of the milk, there are a number of things you can do:

- *Stand in a hot shower and let the water run over your breasts. This can stimulate some milk release and help you to feel less full.*
- *Sit in a warm bath and lean into the water. This will allow some milk to leak out*
- *Express just enough milk, by hand or with a breast pump, to make yourself feel more comfortable.*
- *Wear a comfortable but supportive bra that does not restrict your circulation.*
- *A traditional remedy for engorgement is to place cabbage leaves inside their bras to slow milk production. Wash cold, raw, green cabbage leaves and crush the leaf veins to release the enzymes. Replace the leaves about every 2 hours as they wilt.*
- *Apply ice packs for 5-15 minutes at a time to your breasts to reduce swelling and pain.*

Although you are allowing milk to flow, this will not increase your milk supply. Allowing some milk to flow will decrease the chance of plugged milk ducts, infections, and serious engorgement.

You should watch for blocked ducts, which will appear as tender and painful lumps in your breast, or a breast infection which would manifest itself in a tender, reddened area and would be accompanied by a fever or chills. Should either of these conditions present, contact your GP, midwife, or a lactation consultant for further assistance.

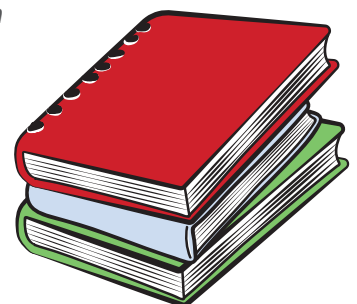
Donating your breast milk

For some mothers, it can be healing to pump their breast milk and donate it to another baby in need for a short while. Breast milk donated can be lifesaving. To begin the donation process, visit Mother's Milk NZ www.mothersmilknz.org.nz and they will be able to advise you of their donation process. As part of this we recommend you think about how you will bring your donations to a close as some find this has a sense of another goodbye which can be overwhelming, so it is important to protect your mental and emotional help.

Understanding Grief And Your Emotions

The Skylight handbook "Beyond Words - Grieving when your child has died" offers a vast amount of useful information, support options, and ideas that may be helpful for you. This can be purchased online from the Skylight Trust www.skylight.org.nz. Here are some excerpts from the handbook, 2014 New Zealand and Australian Edition (3rd Edition):

- › **"Grief is the combination of all the thoughts, feelings and reactions we have when we're faced with a difficult loss. It's the way we gradually adjust our life to the reality of what's happened - even when we wish it never had. It's a process, and it takes time. How long it takes is different for everyone." (Page 6)**



› Common reactions of bereaved parents (Page 8)

Emotional

- Shocked - stunned - disbelieving
- Numb - empty
- Desolate - despairing
- Sad - sorrowful
- A deep emotional ache

Physical

- Crying - moaning
- Shouting - yelling - screaming
- Agitated - hard to sit still - highly energised
- Tired - exhausted - needing to sit or lie down
- Sleeping more or unable to sleep much at all

Mental

- Blank - hard to think
- Confused - disoriented
- Hard to concentrate
- Forgetful
- Slow responses to things

Social

- Needing to talk with others often - or wanting to avoid talking to others
- Wanting to be with people - or wanting to be alone more
- Needing to be doing things most of the time - or needing to avoid commitments and doing as little as possible

Spiritual

- Seeing, feeling or sensing the presence of your child who has died
- Asking "Why?" or "Why not someone else?"
- Turning to your beliefs or away from them



› Difficult conversations with others (Page 16)

- You only have to share information with the people that you want to share it with.
- If you are finding it too hard to have lots of people wanting to contact you, consider using an answer phone or placing a sign on your door.
- Accept that some people just won't 'get it'
- Realise that, in the coming days, weeks and months there will be people who haven't heard, and you or others may need to tell them. You may like to find a sentence or phrase that you can repeat about what's happened so it becomes a little easier.

› The darker side of grief (Page 67)

- If the pain of your grief remains extreme for more than six months and if it is the only focus in your life, your grief might be considered to be complex. If this sounds like you or your partner, it's very important to seek professional support from a doctor, counsellor or psychologist. You don't have to bear this intensity of grief without help and support (see page 85).

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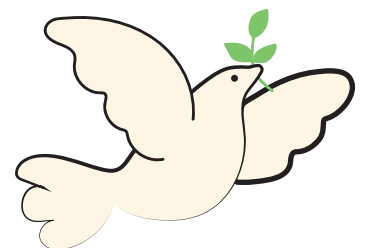
- If you have suicidal thoughts, it is very important to talk these suicidal thoughts through with your doctor or counsellor as soon as possible. *Suicide Helpline: 0508 828 865 (available 24/7).*
- Using alcohol or drugs or taking risks, may temporarily reduce the feelings of grief in the short term. However, they can also cause you physical harm, damage close relationships, create a dependency, increase the feelings of grief and depression and also complicate your daily life even more. *Alcohol and Drug Helpline: 0800 787 797; Gambling Helpline: 0800 654 655.*

Sources Of Community Support

- *Skylight - Supports people of all ages who are facing any kind of tough life situation, specialising in grief, loss, and trauma (www.skylight.org.nz)*
- *The Grief Centre - Provides transformative support through all forms of loss and grief (www.griefcentre.org.nz)*
- *Sands - A volunteer, parent-run organisation to support parents after miscarriage, stillbirth or when a baby has died, with local branches (www.sands.org.nz)*
- *"The Joyful Mourning" - A podcast for women who have experienced pregnancy or infant loss (www.themorning.com/listen, on Spotify, or on your favourite podcast app)*
- *The Grief Centre offers a bereavement support service and counselling*
- *Baby Loss NZ - Offers a range of leaflet resources with support information for those who have experienced, and/or are affected by the loss of a baby or child (www.babyloss.co.nz)*
- *Whetūrangitia - Offers information for family and whānau experiencing the death of a baby or child (www.wheturangitia.services.govt.nz)*

Creating More Memories

- *Timmy Smith's Bespoke Collection - Designed to allow you to carry the memories of your loved one (www.timmysmith.co.nz/collections/bespoke-collection)*
- *Fingerprints - Capture a moment in time with one of our pure silver pendants imprinted with your loved one's fingerprint, foot and handprints, name or artwork (www.fingerprints.co.nz)*
- *Remembrance Glass - Enclose the ashes of your loved one into a hand-blown glass sphere, or touch stone providing you with an object of beauty to treasure forever (www.remembranceglass.co.nz)*
- *Flame Art - Ash from cremation can be incorporated into a glass bead, sealed internally and either visible or shielded from view with coloured glass (www.flameart.co.nz)*
- *Hamilton Lifecasting Studio - Preserving family moments in 3D form (www.hamiltonlifecastingstudio.co.nz)*
- *Photo book (e.g. www.snapfish.co.nz)*
- *Engraved keepsake boxes (e.g. www.keeps.co.nz)*



Other Things To Consider

› Returning to work

Returning to work after you have lost your baby can, as impossible as it may seem, be a helpful and healthy way to re-develop a new routine and adjust to this new-normal life. However, ensure that you take the time you need to work out what's best for your mental and physical health. Here are some suggestions:

- *Give yourself time to come to terms with your grief and don't make any rash decisions.*
- *Your maternity and PPL entitlements do not change with your baby's passing so it's your decision how long you take off before returning to work.*
- *If you had a premie, the estimated delivery date (EDD) may be yet to pass, so know that this is likely going to trigger another emotional pain when the date finally arrives.*
- *Consider whether returning to work part-time will be more emotionally manageable to start with and then gradually increase your hours to full-time; speak to your employer about what options they can support you with.*
- *Be sure to get advice from your friends, family, whānau, or even your GP/other professional.*

› Paid Parental Leave (PPL)

- *PPL entitlement is based on your work situation, thus the entitlement does not change with your baby's passing.*
- *If you are returning to work, you'll need to update your PPL information in myIR so that the correct final payment is made to you.*
- *You can find other financial information and entitlements at Whetūrangitia.*

› Life after loss

Listen to your feelings and don't pressure yourself to (as an analogy) go from recovering from a broken leg to running a marathon; try simply putting on your shoes first to see how that feels and if that's comfortable enough, then try taking one step outside; you can stop at any time and decide tomorrow if you want to go further.

This article outlines just some of the ways to assist a family after the loss of a baby.

Should you wish to add to this information please contact us at

info@neonataltrust.org.nz

The Neonatal Trust

www.neonataltrust.org.nz

