

# Stillbirth, Neonatal Death and the Grief Journey

## When our baby dies

Only we know how we feel about our baby who has died. The grief we feel about their death is not equal to the length of time they lived, but rather reflects the love, hopes and dreams we invested in them. There is no hierarchy to different kinds of losses.

As bereaved mum Kaeti observes, 'you become a parent as soon as you see that positive pregnancy test'. Both before and during pregnancy, we often imagine our child and our future with them so that our baby's death is also the loss of these cherished plans and the life we had hoped to live.

Grief often comes in waves. It is common to feel guilt, self-blame, or failure. We also can feel shock, sadness, anger, and disbelief, sometimes moving from one emotion to another in rapid succession. Although it can make us feel like we are going mad, this barrage of emotions is a perfectly normal response to grief.

Whilst it is natural to want to avoid suffering, it is by allowing ourselves to feel grief that we begin to comprehend the reality of our baby's death and slowly adjust to our loss. As psychotherapist Julia Samuel MBE reminds us in Grief Works, 'pain is the agent of change': it is through grief that we 'find a way of living with a reality that we don't want to be true'.



However, grief is exhausting and it is important that we take breaks from the emotional turmoil. We need to find way to distract, sooth and sustain us. We could consider going for a walk, meditating, watching tv, exercising, cooking, gardening, or meeting up with a good friend.

# The physical and emotional impact of grief

When our baby is stillborn or dies in infancy, we will usually be offered choices on what we would like to do in the delivery suite. Everyone reacts to be reavement differently, and there is no 'right' way to respond, but many of us will value these opportunities to make memories with our child. We can hold our baby, take photographs, read to them, and have imprints of their hands and feet taken.

Most of us feel grief physically as well as emotionally. This experience is often heightened for mums after a stillbirth or early death, as we feel all the usual physical sensations following a birth without having our baby with us to care for. Some of us may be upset by our pregnant shape, while others want to retain it as a way of remaining close to our baby. Many of us also find that our arms physically ache as we long to hold our baby.

We can experience vivid flashbacks of the moment we hear about our baby's death, the birth itself, or find it difficult to think of anything other than our baby. Most of us will find these memories become less intense and frequent over time, but there is support

available if this doesn't happen. We might consider having Grief Therapy to help us process what's happened or try Eye Movement Desensitization and Reprocessing therapy (EMDR), an effective treatment for trauma and post-traumatic stress disorder (PTSD).

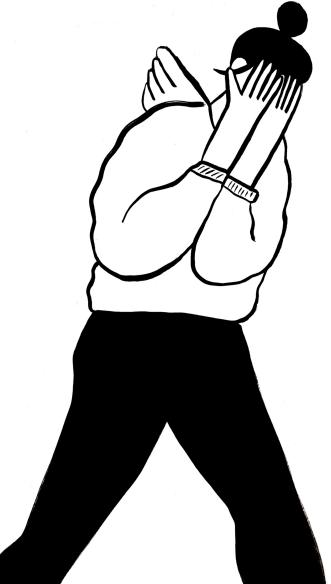


## Relating to our partners and other people

Our experience of grief is as individual as we are. While some of us cry and rage, others experience a numbing state of shock, become angry or withdrawn, or actively try to keep emotions in check for fear they will overwhelm us or distress the people around us.

Grief can affect siblings, grandparents, and friends. We might find that our partners or other people around us respond to the emotional shock differently to us, and this clash of grieving styles can often cause more tension than the loss itself. Although it can be easy to assume that others feel less intensely than we do, it is important to remember that there is no single 'right' way to grieve. We all have our own timeline for emotions and ingrained coping mechanisms and all these responses are valid.

We should try to surround ourselves with as much love and support as possible. Many of us will value opportunities to share experiences with those around us, acknowledging that our baby lived and died and respecting them as a person. We might also find it helpful to talk to other parents who have had similar experiences (which we can do through Sands), or join a supportive community to share our loss and remember our baby with other families.





# Remembering our baby and carrying them with us

Psychotherapist Julia Samuel suggests that externalizing our relationship with our baby can help us maintain our continued bond with them. Physical objects that remind us of our baby often provide valuable 'touchstones to memory' by connecting us with our child in a concrete, sensory way. We might, for example, create a memory box which holds physical reminders of our baby, such as the blanket we held them in or scan photographs. As time goes by, we can add to our box with the letters and cards we write to our child on special occasions and photographs of things we do to remember them. The evolution of our memory box thus can express both our enduring love for our baby and the way our grief journey has changed over time.

Although memory boxes provide a powerful way to maintain our bond with our baby, some of us might find that they trigger flash-backs or a feeling of panic. This can be a sign that we should consider seeking additional support for our grief. We can then return to our memory box when we feel ready.

As time passes, we may look for other ways to stay connected to our baby and integrate them into our lives, finding ways to honour their absent presence on birthdays, religious holidays and special occasions. For example, we can:

- plant or visit a tree that honours our baby
- arrange a birthday party or bake birthday cake
- visit memorial gardens such as the Sands Garden at the National Memorial Arboretum in Staffordshire where we can write our baby's name on a stone and add it to one of the paths
- visit and perhaps scatter ashes in a special place
- arrange a family outing that we might have chosen for our child that year (for example, we could visit the zoo or have a picnic on younger birthdays, and go bowling, to the cinema or a restaurant on older birthdays).

We may also think of other ways to mark the day and we might consider taking time off work to allow ourselves space to focus on our family and our baby. For example, Natalie chose a series of personal celebrations for her daughter's birthday this year: 'This year our family scattered petal confetti in the river for her and had lunch outdoors so that I could escape the feeling of being "trapped" on this day which is a recurring feeling tied to Aurora's death. We then finished the day by blowing bubbles with her brother to send up to her.'





#### Post-traumatic growth

Psychotherapist Robert Neimeyer suggests that we process grief by retelling our story of loss, integrating our loved one into ourselves, and reinventing ourselves and our lives in light of our bereavement. Many of us eventually find that grief also gives us a deeper understanding of ourselves, our relationships, or our spiritual or material world – a process psychologists call post-traumatic growth.

As bereaved mum Lucy explains, 'you can't opt out of trauma, and nor does focusing on the positives make the negatives go away. Finding meaning and purpose on the other side of deep grief required the perspective that only time affords [...] After a year I was able to see glimpses of a possible strength or benefit from the loss of Ada: a renewed recognition of the fragility of life, a profound appreciation of what is truly important – love, kindness, work for the common good. Three years later, the grief remains, but I also feel the love and wisdom she gave us in her short life'.

We can't control our losses, but we can choose the way that we reshape our lives in response to them. Like Lucy, we might discover that we have a greater compassion for others, an enhanced appreciation of those we love, or a new understanding of life's precious brevity. Some of us might also decide to reach out to others through charity work or find other ways of supporting people in need.

While we will never forget our baby or 'get over' our loss, most of us will find that time changes our relationship to grief and we can eventually remember our babies with more love than pain.

#### Bereavement support after the death of a baby

A Child of Mine – Help for Bereaved Parents (www.achildofmine.org.uk); Helpline: 07803 751229

Antenatal Results and Choices (ARC) (www.arc-uk.org); Helpline: 0845 077 2290 or 0207 713 7486

At A Loss (http://www.ataloss.org/find-support/search)

Child Bereavement UK – CBUK www.childbereavementuk.org); Helpline: 0800 02 888 40

The Child Death Helpline (http://childdeathhelpline.org.uk); Helpline: Freephone 0800 282 986 or 0808 800 6019

The Compassionate Friends (www.tcf.org.uk); Helpline: 0345 123 2304

Cruse Bereavement Care (www.cruse.org.uk); Helpline: 0808 808 1677

Lullaby Trust (www.lullabytrust.org.uk); Bereavement Support Helpline: 0808 802 6868

Miscarriage Association (https://www.miscarriageassociation.org.uk/); Helpline: 01924 200799

Petals (www.petalscharity.org)

Sands (https://www.sands.org.uk/); Helpline: 0808 164 3332

**For further resources,** see: https://www.sands.org.uk/usefullinks & http://www.ataloss.org/find-support/search

Written by Lesel Dawson

Illustrated by Jayde Perkin

This booklet grew out of the research and experiences of many people.

Thanks especially for the contributions from:

Danya Bakhbakhi, Peter Byrom, Jen Coates, Lesel Dawson, Cleo Hanaway-Oakley, Natalie Le Grange, Mary Lynch, Kaeti Morrison, Tamarin

Research Associate: Rachel Hare

Norwood, and Lucy Selman.

This work was supported by the Elizabeth Blackwell Institute for Health Research, University of Bristol and the Wellcome Trust Institutional Strategic Support Fund.

## With special thanks to:





Proudly supporting Sands

