

Supporting Parents through Pregnancy Loss and the Death of a Baby

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Who we are and what we do



Fears/Concerns/Challenges

- ✧ When working with parents who are facing the death of their baby, what are your biggest fears and concerns?



Facts and Stats - 2015

- 697,852 live births in the UK
- 1 in every 373 babies born in the UK died in the first four weeks
- 3,434 babies were stillborn
more than 9 babies every day
- over 900 babies died before reaching their first birthday

CBUK 2016 Impact Report



"The quality of care that bereaved parents receive has a profound effect on their well-being and that of their families, both now and in the future. Good care cannot remove the pain of their grief, but poor care makes everything worse."

(Neil Long, Former Chief Executive, SANDS)



"Stillbirth and neonatal death causes a grief that hurts unlike any other" (Parent)

"Is there ever a right way to help parents deal with this devastating loss?" (Midwife)

"When an adult (or older child) dies, there are tangible memories and reminders. When a new baby dies, parents feel they have been left with nothing."

(J. Schott, SANDS)



Changing Attitudes

- ✧ In 1986...
 - Twin pregnancy
 - Dismissed as “over-anxious mum”
 - Early onset labour
 - No heartbeat detected for either baby
 - Delivered amid fog of valium and epidural
 - Babies taken away
 - Made to sign papers
 - Parents not invited to funeral

Changing Attitudes

- ✧ In recent years
 - Pregnancy loss and stillbirth is more widely reported
 - Media coverage, particularly with high profile celebrities
 - Focus on supporting families
 - Messages of sympathy and kindness
 - Acknowledgement and understanding of loss

The Death Taboo

- ✧ Has the silence/taboo been broken?
- ✧ Greater emotional openness/understanding
- ✧ Parents encouraged to hold baby
- ✧ Memory boxes and keepsakes
- ✧ Photographs, hand and footprints, locks of hair
- ✧ Parents encouraged to be involved in organising the funeral



A Father's Perspective

“Its different because there are no happy memories to sustain you, no sense of who that person was and what they meant to you.” (Father)

“In the natural order of things, parents are not expected to outlive their children. I should not be burying my son, I should not be burying him.” (Father)

“My wife was treated as having lost someone she loved, I was treated as having lost someone I was responsible for.” (Father)

Mother's Perspective

“I will always remember the midwife who looked after us throughout the labour, and when our beautiful son was born dead. She managed to make a terrible event into something that was also very precious. She delivered him with such love and care. Remembering that kindness has kept us going through the darkest times.”

(Bereaved mother)

Loss and Grief

"When reality clashes with the future you had expected"

"Grief is the form loves takes when someone we love dies"

"Grief is just as normal a reaction for staff as it is for parents and relatives"

Hierarchy of Grief

- ✧ Fetal Loss
- ✧ Stillbirth
- ✧ Neonatal Death

Phases of Grief

- ✧ Denial
- ✧ Shock
- ✧ Anger
- ✧ Bargaining
- ✧ Acceptance

(Elizabeth Kubler-Ross, 1969)

Tasks of Grieving

- ✧ Acceptance
- ✧ Experiencing the pain
- ✧ Adjusting to changed world
- ✧ Maintaining an enduring connection

(Worden, 2009)

The Dual Process Model of Coping with Bereavement

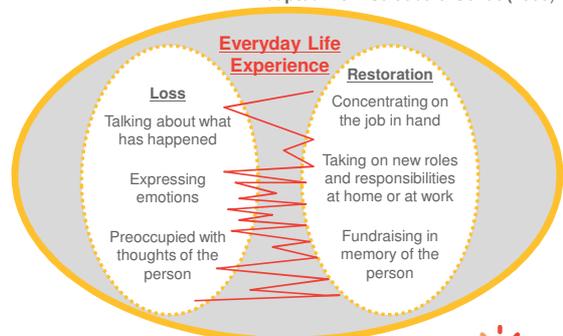
Rationale and Description, Stroebe, M. & Schut, H. (1999)



Death Studies 23, 197-224

A Dual Process Model of Coping with Bereavement

Adapted from Stroebe & Schut (1999)

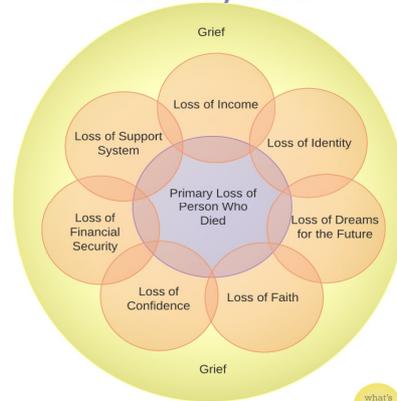


The Grief Journey

- ✧ Acute grief
- ✧ Adaption to loss (mourning)
- ✧ Integrated grief

(The Center for Complicated Grief, 2012)

Secondary Losses



<http://whatyourgrief.com>

what's your grief?

Loss and Grief

Parents often feel:

- **Shock** – *Is there something I did to my baby? Why has this happened to me?*
- **Grief** – *this is not the baby I had hoped for, I have lost my perfect baby.*
- **Guilt** – *I did something in my pregnancy that has made my baby come early.*
- **Denial** – *I cannot bear to think my baby might die. I might try to think everything is alright even when staff are telling me my baby is very, very sick.*
- **Detachment** – *I don't want to get too close to my baby, it is too painful to care deeply and I feel so helpless.*
- **Projection** – *Someone else has caused all these problems.*
- **Anger** – *I want my baby to myself so I can look after him in my way.*



The Deafening Silence

- ✧ Abigail's Footsteps was launched in 2010 by parents Jo and David Ward following the death of their daughter Abigail, who was stillborn at 41 weeks gestation.
- ✧ Their primary objectives are
 - To improve bereavement training for midwives
 - To improve the quality of supportive information that families receive after a stillbirth

Research and Initiatives

- ✧ APPG Baby Loss: www.lullabytrust.org.uk
- ✧ Each Baby Counts – RCOG: www.rcog.org.uk
- ✧ Bereavement Care Pathway – SANDS: <https://www.sands.org.uk>
- ✧ Perinatal Mortality Review: <https://www.npeu.ox.ac.uk>
- ✧ MBRRACE 2015 Perinatal Confidential Enquiry: <https://www.npeu.ox.ac.uk>
- ✧ Saving Babies' Lives Care Bundle – NHS England: <https://www.england.nhs.uk>

Creating memories

- ✧ Memory boxes
- ✧ Hand and footprints
- ✧ Lock of hair
- ✧ Baby photography (Remember My Baby): www.remembermybaby.org.uk



Faith, Culture and Beliefs

- ✧ Family culture
- ✧ In times of stress, people revert to their culturally acquired coping mechanisms
- ✧ We must never make assumptions about bereavement practices based on a person's cultural or religious background
- ✧ We need to ask what is important to them
- ✧ What is the impact on a relationship?

Dos and Don'ts

- ✧ What's ok to say?
- ✧ What's not ok to say?

The impact of this work on us

"The expectation that we can be immersed in suffering and loss daily, and not be touched by it, is as unrealistic as expecting to be able to walk through water without getting wet".

(Remen 1996)

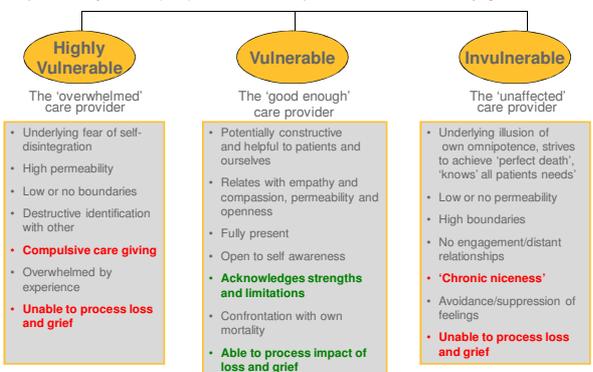
Compassion Fatigue

Secondary traumatic stress/vicarious trauma/burnout

"Compassion fatigue is a gradual lessening of compassion over time, due to chronic exposure to traumatic events, which has a detrimental effect on individuals, both professionally and personally"

(Moya del Pino, 2012)

Adapted from Papadatou D (2009) *In the face of death: professionals who care for the dying and the bereaved*



Take the care of yourself seriously

- ✧ It's impossible not to be affected
- ✧ Parallels in your own life
- ✧ To be a professional professional
- ✧ May be exhausted or in a personal crisis
- ✧ Culture of sacrificing self for others
- ✧ If you never say "no", what is your "yes" worth?
- ✧ Busyness is an addiction and an anaesthetic

Maintaining the balance

- ✧ Reflective practice
- ✧ Staff debriefs
- ✧ 1-2-1 counselling
- ✧ Schwartz Rounds
- ✧ Peer support
- ✧ Training
 - Communication skills
 - Breaking bad news
 - Stress in the workplace
 - Conflict resolution



Compassion Satisfaction

- ✧ The pleasure you derive from being able to do your work well
- ✧ A feeling of pleasure in being able to help others
- ✧ Positive feelings about your colleagues
- ✧ Feeling part of a cohesive and supportive team
- ✧ Feeling that you have positively contributed in your work environment



When a baby dies....

Helpline: 0800 02 888 40

Email: enquiries@childbereavementuk.org

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www.childbereavementuk.org

Reflections on our day



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