

Putting compassion, care and kindness into practice by developing the role of the Bereavement Specialist Midwife.

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### Contents

- Background
- The need for bereavement services
- Patient story
- Our role
- What is bereavement
- Cycles of grief
- Patients feedback
- Getting it right
- Making a difference





#### Background

- At St. Mary's hospital our birth rate is almost 10,000 births a year.
- On Ward 64 we care for approximately 140 families per year who suffer the loss of their baby. This has a huge impact on women, partners, families and staff.
- We recognise the need for a Bereavement Specialist Midwife to support these bereaved families and so the Bereavement Midwife Role was developed in 2013.





# The need for Bereavement service

The care that parents receive around the time of a loss has a huge impact on their perception of what happened and on their ability to cope (SANDS 2010).

### Sarah's Story

- "Benjamin was born 6 weeks early in 1982. He was transferred to the Neonatal Unit quickly after birth but suddenly deteriorated and died before I had been allowed to see him. My husband and I were taken to the Neonatal Unit and I held his beautiful body for two precious minutes before he was taken away. That was the first and last time I ever saw Benjamin.
- I was not offered any photographs or hand and footprints, I wasn't offered the opportunity to see him again or to have him blessed. I went home with his name band and a two minute memory of him and absolutely nothing else.
- Not knowing where my son had been laid to rest caused me unimaginable distress.
- With lots of investigation and 6 years after his birth, I found out where Benjamin had been buried. He was buried with two old ladies that had died in the same month and he didn't have a head stone. I now had somewhere to take flowers and remember my first born which brought me comfort for the first time in the 6 years since he had died.
- I am certain that not being offered any memory items, to spend time with my baby or consultation over my sons funeral greatly affected my grieving and still continues to cause me pain 30 years later."

(Sarah, bereaved mother)



# Compassion is the heart of what we do.





#### Our Role

- Meet with parents at diagnosis or poor prognosis.
- Support through their admission on delivery unit, memory making, care of the baby, saying goodbye, mortuary visits, practical funeral support.
- Development and renew facilities for parents and for deceased babies
- Postnatal follow-up calls and postnatal appointment attendance.
- New starter induction day and staff training.
- Developed the bereavement steering group.
- New guidelines and pathways internally and regionally with the SCN.
- Questionnaire development and remodelling care to meet needs.
- Coffee mornings for feedback and support for parents.
- Pre-conception appointments.
- Next pregnancy support and bookings.
- Rainbow clinic.



#### What Is Bereavement

- Numbness
- Yearning & searching
- Disorganisation
- Isolation
- Incomprehensible
- Death of a person who could have been
- Part of them dies
- Lack of understanding
- Private



#### The Pain

"I just want things to be normal again, I want the hole inside me to fill up, I want to sleep at night without sobbing my heart out, most of all I want my baby. I scream inside for her, I want a lot, don't I? Some I can have, one I never will."

(A bereaved parent)





## Grief Is

Learning to rebuild lives

Guilt

Isolation

Loss of a future /shattering of dreams

Despair

Vulnerability

Natural

Integrated into everyday life



#### Grief is not?

- A disease that you can recover from.
- A measure on time
- A time limit
- Something you forget
- 'At least you can get pregnant'





#### Parent's Feedback

- Bereavement survey and coffee mornings
- The feedback is very positive

"We will always be hugely grateful for the wonderful care we received even if the outcome wasn't what we would have wished for" (bereaved mother)

"Thank you for everything you did for our little family after the sad loss of our son. The support you gave to us at the worst time of our lives was amazing and we will always remember you" (bereaved mother)



#### Getting bereavement care right

"You can make the worst experience of someone's life as good as is possible, by your caring compassion, empathy and listening..."

Mel Scott, After Finely



# The impact for parents if we don't get it right:

"I felt I should've been offered the chance to bathe and dress my baby. I think someone from the bereavement team should have come sometime after the birth to talk through these things that you need to do but can't think for yourself or don't know enough to ask about them"

"The midwife who delivered my baby had not experienced a stillbirth and did not invite me to hold my baby - a simple thing – but I dared not ask at the time. Luckily at the funeral directors, I asked and got to properly hold him"



#### Making a difference

- Build a rapport with the parents in your care.
- Good Quality memory making(Photographs, Hand and footprints ink and casts, Blessings, remembrance books, Memory trees, baby memorial services.)
- Acknowledge the baby.
- Spend time asking parents what their expectations are.
- Ask parents regularly, but indirectly if you are meeting their needs.
- Spiritual support
- Improve communication across teams.
- Simple steps on your unit if you don't have a bereavement midwife (door plagues, contact number cards, set up a bereavement email, improve resources on your unit, approaching charities).
- Staff training on mandatory training or outside agencies



# Before





# After (It's the little Things)





# Examples of what to say

I'm so sorry to be meeting you in these circumstances and I'm so sorry to hear about Harry.

I cant imagine what you are going through right now.

Its right that you should feel sad and in shock, what is happening to you is devastating.

I don't have the words to make it better but I'm here for you.

It is normal to cry and not know how to stop.

Harry is beautiful, can I meet him.



#### Take home message

"Overall, despite the horrifying fact that you have lost a child, my experience of pregnancy, labour, delivery, birth and aftercare has been positive. I have some wonderful mementoes of my child and I was made to feel like she was as important as a baby who was alive and that was the most important thing for me"

(Listening to Parents NPEU University of Oxford 2014)



# Useful information

Victoria Holmes & Emma Lane 0161 701 5022

Bereavment.Midwives@cmft.nhs.uk

Sands

www.uk-sands.org

Child bereavement Trust

www.childbereavementuk.org

Miscarriage association

www.miscarriageassociation.org.uk

4Louis

www.4louis.co.uk

Winston's wish supporting bereaved siblings

www.winstonwish.org.uk