



This article is based on a case study by a third-year student midwife who, in the course of writing up an assignment on stillbirth for her degree, opened up discussion with her own mother who experienced a stillbirth 40 years previously. The discussion demonstrates how changes in bereavement care over four decades affected one woman, her partner and her family. Good practice following stillbirth and subsequent bereavement care is discussed, following Stillbirth and Neonatal Death Society (SANDS) guidelines (2016), which make recommendations for good practice.

BEREAVEMENT CARE 40 YEARS ON



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INTRODUCTION

A stillbirth is a baby born with no signs of life, known to have died after 24 completed weeks of pregnancy. There were 5,623 registered deaths of babies, in 2014, who died after 24 weeks and within four weeks of birth (Manktelow et al 2016). Experiences of bereavement can have profound emotional, psychiatric and social effects on parents, relatives and friends (Heazell et al 2016; Royal College of Obstetricians and Gynaecologists [RCOG] 2010; Cacciatore 2013). It may

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also have far-reaching consequences for the woman's subsequent parenting skills (Warland et al 2011) and for a subsequent child (Hughes et al 2001).

CARRIE'S STORY

I always thought that my mum and I had a close mother-and-daughter relationship but, while working on the final assignment of my midwifery degree, I discovered a whole new depth to my mum that she had kept hidden for 44 years. I believe her sharing this 'secret' with me has created a mutual understanding and an even stronger bond between us.

In the early 1970s my mother had her first baby: a stillborn female infant. I grew up in a shroud of secrecy and whispers and

heard snippets of conversations about 'the first baby' but we never talked about my sister. While researching studies for my assignment, I decided to talk to my mother about her experience of the care she received while suffering a stillbirth.

It was a difficult conversation to initiate but I asked questions and listened to my mum's answers. She talked and talked. It was as if she had finally been given permission to talk about the first baby.

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She still refers to her as 'the first baby' because she cannot bring herself to say her name, to accept that she had a baby that had died. I realised that this may be the first time my mum may have felt able to talk about her baby and to express her grief.

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NORMAL PREGNANCY

My mum had a normal pregnancy and, like most pregnant women, she was excited about the imminent arrival; she decorated the nursery and bought little outfits and blankets, all neutral colours, of course, as they didn't have ultrasound scans to determine the sex of the baby. My mum went into spontaneous labour. She was not supported emotionally or physically during her labour, and awoke from her anaesthetic to be told by a nurse that her baby had died. There was no choice of seeing or holding the baby or taking photos or pictures or collecting keepsakes: nothing. It was only in the mid-1980s that the death of a baby at the time of birth began to be recognised as a major bereavement. Until then, a baby who was born dead at any age was swiftly removed from the labour ward. The parents were given no opportunity to see or hold their baby.

CHANGES IN PRACTICE

Since then practices have changed and studies have found that giving women the opportunity to see and hold their baby may help them in the process of grieving (O'Leary and Warland 2013; Radestad 2009). National Institute for Health and Care Excellence (NICE)

guidance (2014) and SANDS (2016) recommend that a woman should be given the chance to bond with the infant and say goodbye, if she wishes to. Each woman will feel differently and parents' feelings about this may depend on how health professionals offer this choice. Erlandsson et al (2013) found that if the health professional assumed the parents wanted to see their baby, this felt more natural and comfortable.

My mum had no bereavement care, no acknowledgement by the caregivers of the death of her baby. Her consultant told her she was 'better off' not seeing the baby. Those two little words made my mum think, for all those years, that her baby had been deformed or disfigured in some way. All this meant that my mum and dad grieved in silence, believing they shouldn't talk about what had happened or how they were feeling. My parents must have felt completely isolated, shocked and worried that their feelings and sadness were unacceptable and abnormal.

ISOLATION

After the death of her baby, family friends would ignore my mum if they bumped into her in town and if they did have to speak to her, no-one mentioned the loss of her baby. One afternoon she bumped into a woman who had been pregnant at the same time as my mum and she had her baby swaddled in the pram. My mother came face-to-face with her and she couldn't hold back the tears, they rolled down her cheeks. The woman crossed the road and ignored my mum, pretending she hadn't seen her.

I discovered that my father had arranged for the burial, but they never discussed any aspect of it, so my mother had no idea where or whether her baby was buried. My parents just didn't talk about it. They went home from the hospital and had to pack up all the baby things. How difficult it must have been for them; and they still didn't talk about it.

ECHOES

My mum had my brother a year later. When she was pregnant with me she felt the same movements and cravings that she had had with the first baby. I was born in a doctor's house in the

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outskirts of Lahore, Pakistan, and my mum believed I was going to die. There is research to suggest that women experience some anxiety relating to stillbirth during subsequent pregnancies, so good support systems are important, not just in the weeks after the loss, but also when planning for future pregnancies (Campbell-Jackson et al 2014; SANDS 2016).

A LIGHTER FUTURE

My mum has now found the baby's burial place. She is in an unmarked grave, with 11 other babies, where we will lay some flowers and possibly a plaque. My mother has spent the last 44 years carrying around her secret grief like a burden and now she seems a little bit lighter. The memories of that day, things that were said, things that were done – or not done – are still upsetting for my parents, decades later, but they are comforted, knowing of the changes in practice. Initially as a student midwife I had no sense of the bereavement of a mother when her baby dies. As I have cared for and spent time with women who have suffered loss, I understand a little bit

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more every time. One of the biggest things I have learned as a student midwife is that I am not afraid to talk about and acknowledge the death of a baby. And finally how proud I am of my mum for completing her journey and commemorating my sister's death.

DISCUSSION

A chance to mourn

Nowadays, health professionals are far more aware of the impact of the death of a baby on the woman and her family. The SANDS (2016) and RCOG (2010) guidelines stress the importance of good physical and emotional care for women who have a stillbirth, to help identify and minimise psychological and physical ill-effects. Parents are offered opportunities to see and hold their baby, to name him or her, to collect keepsakes, and to make their own decisions about funeral arrangements and memorials. Since 1992, babies who are stillborn after 24

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completed weeks of pregnancy have to be registered, which means more parents have a certificate to provide official recognition of their baby's existence. Increasingly, people in wider society also recognise that the death of a baby before or around the time of birth is a major bereavement and has life-long consequences.

Wider family

SANDS (2016) highlight the need to acknowledge the grief of partners or other family members who may be severely affected with depression or anxiety (Lee 2012), and that parental relationships have a higher risk of dissolving after stillbirth (Gold et al 2010). Counselling should be offered to all women and their partners and they should be advised about support groups.

CONCLUSION



This case study has highlighted the long-term effects on a woman and her family following a stillbirth, and that there is healing in being able to acknowledge and express feelings and experiences, even if this is many years after the event. The unique quality of the relationship created by the midwife and experienced by the parents at the time of a stillbirth will continue to influence a woman for many years to come. **TPM**

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