

## WORKING WITH BEREAVED PARENTS

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*Shirley Seabury is a bereavement counsellor working within West Lothian Healthcare NHS Trust. She has extensive experience with parents whose baby has been stillborn or has died shortly after birth. In the following article, Shirley reflects upon her role, and adds her own perspective in the light of the publicity surrounding the retention of organs at AlderHey, and in Scotland, the McLean Report.*

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In 1979 I completed my midwifery training, and have worked as a midwife ever since, both here and in the middle east. Of course, I came into contact with women who were mourning the loss of a baby, and although I was competent in my work, I gradually became aware that I sought wherever possible to distance myself from their grieving. I could not cope with grief like theirs, and so I felt that somehow a dimension of my work was lacking. In response to this, I decided to undertake training in counselling, and this training gave me a much heightened awareness both of my own needs, and of the needs of the women with whom I was coming into contact. I approached my then manager, and suggested that I might offer formal counselling to those women who might be in need of it. My manager was only too aware of the need, but was initially unable to obtain the funding. The stark choice was put to her ; either gain a counsellor, or retain a midwife. If you acquire a bereavement counsellor, then you will lose a midwife.

Around this time I happened to attend a study day at which I met Jenni Thomas, director of the Child Bereavement Trust. This charity funds posts of the type which I wanted to establish, and the upshot of our meeting was that the charity agreed to part fund me for two days a week over two years, with the hospital trust funding the balance, and taking total financial responsibility at the end of the two years. This proved acceptable, and so in October 1998 I began working as a bereavement counsellor. At the end of two years, however, I found myself snowed under with referrals, to the extent that two days a week ceased to be realistic. I have now therefore

been appointed to a full time post as bereavement counsellor, with a remit which covers both grieving parents and midwifery staff.

Of child bereavement, the McLean report says, 'The death of a child is a reversal of the natural order, and parents clearly feel the need to continue to protect the child after death, as they have in life.' My experience bears this out absolutely. Mothers especially suffer so terribly from feelings of guilt; the child whom they ought to have protected, sheltered in their womb or in their arms, has died, and so they must have been culpably deficient in their mothering. The deep maternal response is often, 'My child is dead. I ought to have been able to do something to prevent that from happening.'

That sense of protectiveness also affects how parents, again, especially mothers, respond to requests that their child should undergo a post mortem. Mothers have said to me, 'No, my baby has been through enough.' The urge is to nurture, to go on sheltering, even in death. On a personal note, I carry a donor card, and my own parents have expressed unhappiness about this. My mother says that if I died, she could not bear that any further harm should come to my body, even after death. The instinct to nurture a child does not go away, even when the child has grown up. You can see that same instinct at work in the way parents tend a baby's grave, and in the distress which they experience if the grave is upset or disarranged, even by the wind.

As far as post mortems are concerned, of course, in my midwifery days, I was involved with newly be-

reaved parents in asking permission for a post mortem to be carried out, if the reason for the baby's death was not clear. Consent had to be sought sensitively, and I was always on guard in case my status as a professional person in this situation should influence unduly the parents' decision. Despite the natural fears and misgivings, most parents were willing to give consent, on the basis that the post mortem would supply the reason why their baby had died. They saw this as something good coming out of a situation of heartbreak. In West Lothian, for the past few years, parents have been offered access to a summary of the post mortem report, couched in less technical language than the full report.

The events surrounding AlderHey have certainly affected the parents with whom I come into contact. Even some families whom I saw years ago have phoned me up in some distress, wondering whether their baby's organs are still stored somewhere. Part of the reaction is that people feel that they were not asked for their permission; if they had been asked, many would probably have consented. One family who remembered reading some technical reference in the post mortem report to the appearance of the baby's lungs, expressed to me their fear that the lungs had been retained 'to show people'. I was in this case able to find the relevant information, and to reassure them that this was not the case.

I am a trained counsellor, and so in my interactions with parents I am, as it were, in counselling mode. I am also a Christian, with deeply held beliefs which sustain me. Sometimes the counsellor in me listens and discerns a need within parents for something more than counselling, some kind of spiritual comfort or hope. Of course, if parents are hurling blame at God, then it would not be appropriate, from a counselling or from a Christian perspective, to attempt to defend God! But at times parents will talk, almost wistfully, of 'where the baby has gone', and will express a sense that 'my baby has gone to a better place'. One parent asked me about the Roman Catholic doctrine of Limbo. Was the (unbaptised)

baby there? I wrote down the helpful, simple pastoral comment which the priest made to me. 'All babies are created by God, loved by God, and safe in God's arms.' I believe this personally, and I also believe that this is what bereaved parents often yearn to hear.

I also see a spiritual need in the requests I have had from parents, some of whom lost their babies decades ago, that the grave be located. Many parents don't know where the baby's body was buried, and long to find out, perhaps so that a special place can form the focal point for their thoughts and prayers, or perhaps so that they can, by tending a special place, continue to care for their child. I suppose that in our sometimes irrational fears and reactions around death and the fate of the body after death, we are so trapped in a literalistic way of imagining heaven, and time, and the resurrection life. Our imagination, our understanding are so limited.

It is stressful to be constantly working with bereaved parents, and sometimes I do feel burdened and drained. When that happens, I sometimes go to the chaplain, just to talk things over and recover a healthier perspective. I also have excellent supervision from a family therapist, who is very skilled in helping me to separate, or to link what's mine and what belongs to work. As for spiritual renewal, it comes through prayer - often in the car - and through the support of my housegroup. At times I get angry with God, and find myself echoing the horrible 'why?' questions which I hear so often from grieving parents. That's OK, and I know that God is big enough to absorb my anger. Deeper than the anger, though, there is a sense that, limited as we are, we can only rest and trust in God, who is in control even when our understanding is so sadly lacking. Without that sense of resting ultimately in God, I would risk being overwhelmed by the particular and terrible anguish which is child bereavement.

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