



The death of a baby before, during or shortly after birth: Good practice from the parents' perspective

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Summary This chapter is adapted from *Pregnancy Loss and the Death of a Baby: Guidelines for Professionals* (3rd edition) by Judith Schott, Alix Henley and Nancy Kohner, published by Sands (the UK Stillbirth and Neonatal Death charity) in 2007. The article highlights those aspects of care given to families facing perinatal loss that parents value and those that add, often inadvertently, to their distress. It is based on research findings and on views expressed by parents.

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Introduction

*'Bereaved parents never forget the understanding, respect, and genuine warmth they received from caregivers, which can become as lasting and important as any other memories of their lost pregnancy or their baby's brief life.'*¹

The care that parents receive around the time of a loss has a huge impact on their perception and memories of what happened, on their ability to cope at the time, and on their long-term well-being. Good care cannot remove the pain and devastation that parents feel, but insensitivity and poor care can and do make things worse. There is much that doctors, midwives and nurses can do to ensure that the memories that parents take away with them are as positive as possible.

Everyone we came in contact with that night, the nurse, the registrar, the consultants, they were so fantastic.

They took time to talk to me. And they really showed how upset they were as well. (Bereaved mother)

Parents value empathy and kindness

Parents value empathy and kindness as well as professional expertise. They remember those staff who sensitively acknowledge the enormity and the sadness of what has happened, even if those same staff – with all their experience – feel in their hearts that the outcome was inevitable, or even for the best. They value those staff who remember that their baby is a person and who respect and care for him or her as a precious individual who matters.

Offering this kind of empathetic support is difficult. What is right at one time may be wrong at another, and what is right for one parent may not be right for someone else. Sometimes it is best just to listen, at other times it is appropriate to offer information or suggestions. However, although giving empathetic care can be very difficult, this should not be a reason for doctors and other staff to distance themselves or to be over-cautious about what they say and do. There are also bound to be occasions when a sensitive and thoughtful member of staff 'gets it wrong'

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for a particular woman or couple. When this happens, it is essential that the member of staff is actively supported, not blamed; that senior staff and colleagues recognize that he or she was doing their best in a very difficult situation; and that he or she is given time to reflect, encouraged to continue to offer empathetic and supportive care, and offered training if necessary.

Parents value language that acknowledges their baby

The heightened emotions and stress that parents experience at a time of pregnancy and child-bearing loss often make them very sensitive to other people's language and non-verbal behaviour, especially when those people are 'in authority'. Although it may be clinically correct to talk about the 'products of conception', the 'embryo' or the 'fetus', most parents talk about their 'baby' from the beginning of the pregnancy and are often upset and hurt by clinical terms that seem to belittle his or her importance.² It is important to listen to the words that the woman and her partner use and to use these words in discussions and explanations. Once the baby's sex has been identified, staff should normally use the correct pronoun: he or she, him or her. If a baby is stillborn or dies shortly after birth and has been given a name by the parents, staff should normally use the baby's name when talking about him or her.

Parents value staff who listen

Finding time to listen to parents is difficult for increasingly hard-pressed staff. It can also be tempting to do or say something rather than to listen. But parents value staff who:

- are prepared to listen when they want to talk about what they are going through or about what has happened;
- accept what they say without comparison or judgement;
- remain calm when they express strong feelings and avoid platitudes and empty reassurance;
- respond with empathy, acknowledging their feelings and expressing sympathy and sorrow when appropriate;
- whenever possible, enable parents to have control over what happens and what they do.

Before they go home after a pregnancy or child-bearing loss, all parents should be given opportunities to ask questions and talk at length with staff about anything that concerns or worries them.

Parents value staff who keep them informed

Good communication builds trust, and parents need to be able to trust the staff who are looking after them and their baby.³ The manner in which parents are given information is very important: parents are much more likely to believe information if they feel that the person who is giving it cares.⁴

It may be necessary to repeat information on several occasions; stress and anxiety affect people's ability to take in and remember what they are told. Whenever possible, parents should be offered an opportunity to discuss important matters together, and in a quiet room. They should be

encouraged to ask questions, and to say if there is anything that they do not understand. In between formal discussions, parents should have easy access to members of staff who can answer their questions.⁴

Parents need to feel that all members of the team caring for them and their baby are competent and well-informed. It is essential that information is shared both up and down the hierarchies and across disciplines. All discussions with parents should be documented so that every member of staff who cares for them knows what has been said and what has been decided. To ensure good communication between staff, it is good practice to have a differently coloured sheet in the front of parents' notes where staff can record what they have been told. All staff should check this regularly. It is important, for example, when parents have made a decision, that other members of staff know about it and do not keep asking them about the same issue. If this happens, parents may feel that their decision is being questioned and lose confidence in themselves. It may be also helpful to have designated members of staff who take the main responsibility for checking that the parents feel informed and listened to, for raising sensitive and difficult issues, and for discussing decisions with them.

Breaking bad news

Breaking bad news is difficult and stressful.⁵⁻⁷ Although breaking bad news well cannot reduce the pain that parents feel, breaking bad news badly is likely to increase both their immediate and their long-term distress. Statham et al.⁵ found that even when parents had been devastated by receiving bad news during pregnancy, if they felt that it had been given with warmth and affection and that they had been treated with respect and sensitivity, most had positive memories and were grateful to the staff involved. In contrast, parents had only bad memories if the information was given badly, if the person giving it seemed not to understand the significance of what he or she was saying, was excessively blunt, or was not supportive. Bad news given insensitively can affect parents' long-term well-being.⁵

In general, parents appreciate an indication that the member of staff understands the impact of what they are saying. Phrases such as 'I am afraid it is bad news...'; 'I am sorry to say that the results are not what we expected...'; or 'I am afraid this is not the news you wanted...' may be helpful. Staff should:

- ensure that parents have sufficient time to take in what they have been told, to formulate their questions, and to express their concerns;
- balance honesty and realism with sensitivity and support;
- avoid medical terminology whenever possible, and make sure what they are saying is clear to parents (for example, saying 'your baby's heart is no longer beating' rather than 'there is no fetal heart');
- say when things are not certain and acknowledge the difficulty for parents of tolerating this;
- express sympathy and sadness.

For staff, one of the hardest aspects of breaking bad news to parents is not knowing how they will react and

having to deal with their responses. These may include, for example, stunned silence, disbelief, distress, anger, blame, guilt, or tears. Distress and grief are very hard to witness, especially for people who have been trained to solve problems, find solutions and ease pain.

There is a tendency to react to tears as one does to a haemorrhage. However, crying is a release, and parents value the support of staff who can cope with their tears without embarrassment.⁶ Many people react to bad news and shock with anger, and look for someone to blame; this should not be taken personally. Remaining calm and supportive and allowing parents simply to express their pain can be very helpful.

Offering informed choices

It is never possible to guess what will be important or helpful to anyone who is experiencing pregnancy or child-bearing loss, but it is possible to offer informed choices and to ask. Many parents in these situations feel that they are caught up in a whirlwind over which they have little or no control. Even if they cannot change what is happening, understanding it and making – or participating in – decisions can be very helpful and may help them to feel that they are 'proper' parents.⁴

Whenever there is a decision to be made, the mother (before the birth) and parents (after the birth) should be supported and encouraged to think about what, for them, would be the best thing to do. They are the only people who can say what they want, and they will have to live with the consequences.

Parents need impartial and objective information in order to make choices that are consistent with their own values, their views of their obligations as parents, and their knowledge of their own situation and their short- and long-term capabilities.⁸ The staff giving this information also need to have considered their own values and beliefs and to be aware of what they would decide in this situation, so that they can consciously put all this to one side and be sure that their preferences are not influencing the way that they talk to parents.⁹

The degree to which individual parents want members of staff whom they trust to be involved in making the decision, or to advise and guide them, differs. Some parents prefer to make decisions independently once they have the necessary information. Some prefer staff to help them to work out what they want to do. Others want staff to suggest to them – or even to tell them – what to do.¹⁰ Some parents ask other family members or religious advisers for advice or decisions. In this case it is important that staff clarify with the parents as soon as possible what the roles of any additional participants should be¹¹, and ensure that the mother or the parents give or refuse consent in their own right. It is also important not to assume, for example on the basis of a woman's ethnicity, that she does not want to make independent decisions.¹²

If parents ask staff for advice and guidance, it can be tempting to 'help' them and to steer them towards the option that the member of staff thinks best, or that fits in with normal hospital practice. However, this option may not be right for the parents and may cause lasting regret. By reducing their autonomy it may also damage their

confidence and feelings of self-worth.¹³ At such a traumatic time parents can find it particularly difficult to refuse what may seem like instructions or recommendations from staff.¹⁴

Most parents want to feel guided, assisted and listened to, but not directed or controlled, and certainly not abandoned. One way to help is tentatively to offer examples of things that other parents have done. For example: 'There are several options, some parents choose ... Others decide ...'. Such examples may help them to clarify what they do not want as well as what they do want.

Creating memories

Perinatal loss is unique in that it is the loss of someone very important who has already changed the lives of the parents in fundamental ways, but of whom there are few or no tangible memories and often no memories that can be shared with other people. If the baby miscarried or was stillborn, the parents have never seen their baby alive, and in early pregnancy loss there may be no body. At the same time, most parents feel a strong desire to cherish and remember their baby, and to preserve his or her continuing importance in their lives. Physical items connected with their baby may help to confirm the reality of his or her short existence and provide comfort as well as a focus for their grief in the longer term.¹⁵

Many parents are too shocked and distressed to think about creating mementoes at the time of the loss, especially if it is sudden and unexpected. Most are very grateful afterwards to staff who suggested that they might want to create or collect mementoes of their baby and who have helped them do so. Depending on the type and timing of the loss, these might be, for example, scan photos, a record of the cardiotocography (CTG) trace, name labels, photographs, and/or the clothes the baby was dressed in. Parents should also be offered good copies of consent and any other forms they have signed. For losses at less than 24 weeks' gestation, when there is no official registration certificate, parents may be grateful for the offer of a well-designed and -produced certificate from the hospital confirming their baby's brief existence. (For a downloadable example see the Sands website, <http://www.uk-sands.org/>; click on Improving care > Resources for health professionals.)

When suggesting to parents that they might want to create memories of their baby, staff should remember that parental choice is paramount. As in all care, it is essential to offer genuine choice, and not to steer parents towards a particular course of action in the belief that it will help them. Timing is also important. Parents often need time to think about what they want or do not want, especially if the idea is new to them. Women should not be expected to make decisions when they are in shock, straight after what is likely to have been a stressful and traumatic labour, or when they are still affected by opiates or a general anaesthetic. They should be offered time to make decisions and enabled to take important steps at their own pace.

Communication between staff

The number of staff involved in the care of the mother or parents – and who should be informed – will vary

depending on the type of loss and whether the baby dies before or after birth. However, the mother's GP or primary health-care team should always be informed about the loss within 24 hours,¹⁶ and a designated member of the hospital staff should be responsible for this. The information should be given by telephone, in most cases before discharge, and also as soon as possible by letter, giving a full history. Provided that the parents consent, other staff in the hospital and the community who have cared for them – and where relevant their baby – should also be informed as soon as possible, so that they can offer their condolences and support and can avoid making inappropriate comments if and when they see the parents.

It is also important to inform other staff who will continue to care for the mother and the family. In the case of a stillbirth or neonatal death, for example, this should include the doctor and the midwives who will see the mother for her postnatal check-up, and the staff responsible for inviting parents to bring their baby to clinics or for immunization. The Sands teardrop sticker can be used to identify the notes of a mother whose baby has died at any gestation, both in the period following the death and in any subsequent pregnancies. It can be used on hospital and GP records, antenatal notes and appointment cards to ensure that everyone who comes into contact with her is aware of her loss and does not inadvertently say things that will add unnecessarily to her distress.

Parents who speak little or no English

Members of some minority ethnic groups, refugees and asylum seekers have a higher risk of pregnancy loss¹⁷ and are also less likely to speak English. Even those people who normally speak good English may find that distress and anxiety drastically affect their ability to understand what is said and to express themselves. Communication underpins all the aspects of good care discussed in this article; good care is not possible without communication. Staff caring for parents who do not speak fluent English should have easy access to trained and experienced interpreters. An interpreter can both translate what is said and also help explain to both staff and parents any cultural and other issues that may be hindering mutual understanding.

Specific details of good practice for different situations

For more specific details of good practice in care for parents whose baby dies at any stage during pregnancy or during or after birth see *Pregnancy Loss and the Death of*

a Baby: Guidelines for Professionals (3rd edition) by Judith Schott, Alix Henley and Nancy Kohner, published by Sands (the UK Stillbirth and Neonatal Death charity) in 2007.

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