Information and Support to Parents who Lose a Baby Perinatally

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'The child was dead. I felt as if the ground had collapsed beneath me. I was completely empty inside. I was shaking all over as if I was feeling cold, but it was a cold that could not be warmed with blankets.'

How can you support mothers and fathers whose baby is stillborn or dies with the first days postpartum? Is it a help for parents to see the body, to go to the funeral? These and many other questions arise when dealing with perinatal death.

Between 1979 and 1989, I was in contact with more than 300 mothers and their partners (about 600 people) at the Odense University Hospital who had lost a baby perinatally. About 200 of these participated in our support groups. During this time, our way of handling the situation for these bereaved parents changed radically.

In 1979, it was common practice for parents not to see their dead baby. The hospital usually took care of the funeral, believing that the best way to help the parents was to protect them from reality (i.e. the dead baby). Investigation has shown that this practice can result in psychological problems later. So we now try to bring out what was previously hidden away: we make their loss visible. The parents are allowed to see the dead baby. We encourage them to call him or her by name and to go to the funeral. We stress that there was a child who was born and died, their child.

What follows is a description of the methods we have developed in this department during the last ten years to support these parents.

Support at delivery of a dead baby

- The father is encouraged to stay beside the mother during the entire labour and childbirth.
- The parents are encouraged to see and hold their dead baby. Before autopsy they are able to see the baby as much as they want to. After autopsy they can see the baby in the mortuary.
- The parents are encouraged to name the baby.
- Photographs of the baby are taken just after delivery. If the parents wish it, they can have the photographs immediately. Otherwise they are informed that these are being kept with the maternal records and can be obtained whenever they wish.
- The father is offered the opportunity of staying with the mother overnight in the postnatal ward.
- The postnatal ward staff take care of both parents. While in the hospital the parents are offered further information and opportunities to discuss concerns about pregnancy, delivery and the baby with the obstetrician, the midwife and paediatrician in charge of their case.
- A physiotherapist talks to the parents on one or several occasions, when the mother is instructed in postnatal physiotherapy.
- A social worker pays one or more visits to the couple in the postnatal ward to discuss the funeral, sick-leave and other practical problems.
- The couple is encouraged to arrange and attend the funeral, as well as to involve other children and the family in an open way, saying good-bye to their little brother or sister.
- The mother is informed that she has the right to have 24 weeks' sick-leave and the father to have two weeks' sick-leave, like all other Danish new parents.
- It is very important, at this stage, to discuss the role of the father stressing that he has lost a child as well, and cannot be expected to be the only one to comfort the mother. The couple need to grieve together and to give mutual comfort. They cannot expect to make each other happy. The only real comfort would be to have their baby back again. The father is usually very relieved to hear this.

Support groups

After discharge from the hospital the parents are invited to join a group consisting of eight to ten mothers and fathers who have also lost a baby. The group activities take place once a week over a six-week period and are led by a social worker, a midwife and a physiotherapist. The group activities are intended to give crisis support and prevent later problems. Unresolved grief can result in psychological and psychosomatic diseases, abuse of alcohol and drugs, divorce and problems for the siblings.

Since almost all the parents, both mothers and fathers, have tense muscles and psychosomatic symptoms, each group session starts with physiotherapy. This is also helpful for the women, who need specific exercises after the pregnancy and giving birth. The physiotherapy makes it easier for the parents to make the decision to join the group, as the exercises seem relevant, especially for the mothers. It is easier to persuade quiet or inhibited mothers to come and do exercises than to share their feelings with others. Many of these mothers would otherwise tend to withdraw and get depressed. The fathers may acknowledge their own need for help, or they may say they come for the mother's sake. More than half of the mothers join the group. If a mother has a partner, he will come too in most cases.

Physiotherapy

We start with warming-up exercises for the whole body. For the mothers, the exercises focus specifically on the muscles of the pelvic floor, the abdominal wall and the back. After these exercises, the couple give each other a massage with a massage roller which helps them rediscover one other. It can be very difficult to have sex after a stillbirth. The sexual intercourse reminds them of the birth and of death, and therefore arouses some very strong emotions in them. Using the massage roller together, they touch each other in a 'harmless' way which helps them to get close again. It is also very good for the couples who find it difficult to give each other support. Finally the parents participate in autogenic

relaxation and visualisation exercises, lying on the floor.

The physiotherapy is usually enjoyed very much by all participants and seems to loosen up not only tense muscles but also the psyche.

Sharing feelings and experiences

The next 90 minutes are used for discussion and exchange of experiences among the couples. At the first meeting we talk about how they feel about coming, why they want to join the group and what they expect to get out of it. At the following meetings the parents say how they have been since the last meeting. During each session, a different topic is covered.

1st session: what happened?

Everybody needs to describe in detail the events during pregnancy, labour, delivery and the postnatal period, again and again. How did they react? What did they feel in the various situations around the birth? What did the baby look like? What was it like going to the funeral? The participants are encouraged to write what happened, in the form of a diary or a letter to the baby. Many of them do this and say how much relief it gives them. They share their writing with the group at later meetings.

'I was shocked when they told me my baby was dead. I pleaded for a Caesarean section. I didn't want to go through labour, and I didn't want to see the baby, but now I am very happy I did both.'

'The baby was beautiful. He had my nose and my husband's big feet.'

'I went to the funeral to show respect for the life I had been carrying.'

'Instead of being spared, it's much more rewarding to face the difficulties—to fight and win. After the practical matters had been arranged, I felt an inner calm.'

2nd session: how others react

The parents discuss how the other people surrounding the death (grandparents, neighbours, friends) are reacting to the situation, and give each other ideas for handling difficult situations.

'They try to comfort me by saying that many others have experienced the same thing, as if they are saying "don't worry", but it doesn't help me if 10 or 1,000 people have tried it.'

'When I telephoned to tell our friends what had happened, they said "We'll come and visit you when you are over it".'

'Our friends cried when we told them.'

'The best help someone can give is to listen.'

We talk about the siblings' need for an extra hug and assurance that they are still loved, although the parents are distressed for the time being. Many parents describe meeting people who had experienced a stillbirth many years ago but were never allowed to talk about it. They get their chance to talk now.

3rd session: feelings and questions

Why me? Have I done something wrong? Do I deserve this? Am I being punished? Will new disasters hit me? Are my feelings abnormal? We talk about love, hate, sorrow, longing for the baby, anger, guilt, shame, restlessness, lack of concentration and sleeping problems.

'The love we had for the baby we now give each other.'

'I could have hit the doctor who told us the baby was dead.'

'I feel jealous when I see pregnant women.'

'Longing for her feels like a physical pain.'

'Why didn't she give me a signal to tell me that something was wrong?'

'Is it because of an abortion I had 10 years ago?'

'I feel bad that I couldn't give life to a baby.'

'Is it selfish to grieve?'

Previous unresolved loss may increase the strong feelings.

4th session: plans and expectations for the baby

Before this session the parents are asked to write down their feelings about the following subjects:

- What were my expectations about being a father or a mother?
- What was I looking forward to?
- What were my worries during the pregnancy?

The parents' feelings for their baby, even ambivalent feelings, as well as plans and expectations, are discussed in the group.

'I looked forward to the first smile, the first step, to family life, but not to the nights with a crying baby.'

'I looked forward to building a crane for my son, like my father did for me.'

'When my wife told me she was pregnant, I wasn't happy. Could we afford another child? Maybe I don't deserve to be a father again?'

5th session: impact on the parents' relationship

Before the meeting the parents are asked to write down, from their own experience, differences and similarities in men's and women's ways of grieving.

Often couples support each other best the first month and then find it difficult to carry on. The father will be engaged in his work and the mother may feel lonely. Her body reminds her all the time of what has happened. Their friends don't know what to say now. It is a great relief for many couples to learn that other couples have had exactly the same thoughts and problems as themselves.

'My wife will sit down and cry and cry. And I'll go out and work in the garden. She makes me feel bad. I'm glad to hear that you are reacting in the same way, and that none of us are wrong.'

'When I ask her, "What's the matter?", she'll answer, "Nothing", then I'll become irritated, and I look forward to going to work next day. I don't know what to do.'

Body image and impact on sexual life

Physical feelings are discussed. Most of the women feel that they do not like their bodies: they feel their bodies have betrayed them, that they have suffered in vain and got nothing in return and that they do not want to touch themselves.

'The last time I gave birth I just laughed at my slack, pendulous belly. This time I can't stand it. I feel abused. I feel barren and infertile. I am not a real woman.'

'I feel my body belongs to the baby, and I don't feel like being with my husband. I burst into tears when my husband and I are together—I don't understand why.'

'It has saved our marriage to talk this over in the group.'

6th session: the next pregnancy and evaluation

- Do we dare again? What is the risk?
- Why do we want children?
- When will we be ready for another pregnancy?
- Can anything be done by ourselves or the medical staff to prevent the death of our next baby?

'I want to have children to continue my family into the next generation.'

The midwife describes how the hospital can support the parents in the next pregnancy, and answers many questions. The participants usually get a positive response from the staff at the hospital.

We often invite nurses or other staff members to attend the last group meeting to hear the parents' feedback and relay it to the ward. These discussions have changed the way we handle the cases.

Final evaluation of the group therapy

After these six sessions, most of the parents are ready to manage without professional guidance.

'Now I feel like myself again, and yet I have changed.'

'My husband and I have become much more open, and we have talked other things over as well.'

'I have become more mature, and small things don't make us argue any longer.'

Many groups go on seeing each other privately. This seems to be a great help and support, particularly for the mothers in a new pregnancy. It has been very rewarding for us to see the strength the parents have mustered to get through their grief, and to see parents who have been heartbroken, some close to a nervous breakdown, progress step by step to become strong, mature and sensitive people. Many of them develop good listening skills, helping one another.

The two-month postpartum visit to the hospital

Eight to ten weeks after delivery the couple return to the hospital for a meeting, where they are told about the findings of the autopsy and any other investigations which have been performed. They have a discussion with the obstetrician and/or the paediatrician who previously handled their case. Usually the social worker, and a nurse or a midwife familiar to the couple, attend this consultation. We talk to the parents about their present physical and physiological status and their possible need for further support. A few need to be referred to a psychologist for further therapy. Possible investigations and schedules for visits in the next pregnancy are planned. They are encouraged to return before a new pregnancy if they have any doubts.

The next pregnancy

In the next pregnancy we notice a remarkable difference in the reactions between group participants and non-participants. Those who attended the group are generally much more balanced, they accept the plan for control during the pregnancy and usually follow it. The non-group members are much more anxious. They often contact the hospital and demand a lot of extra investigations confirming the normality of their pregnancy, and still they are very worried.

Anni Hansen has written two books in Danish about this project, 'A Grief Invisible' and 'When the Grief Becomes Visible', published by Bog Fan, St. Kongensgade 61 A, 1264 Copenhagen K, Denmark. A 30-minute video is also available in Danish and English. Write to Ebbe Larson, TV-2 Fyn, Ramsherred 10, 5700 Svendborg, Denmark.

BOOK REVIEWS

GRIEF IN CHILDREN
Atle Dyregrov. London: Jessica Kingsley, 1991. £12.95 pb.

Atle Dyregrov's 'Grief in Children' is a book with a tripartite mission: to present two decades of research and clinical experience on the effect of grief in children; to explain for adults the needs of the bereaved child; and to suggest what they can do to help. All three are covered impressively in this volume.

The secret of the book's success lies in the author's decision to opt for a 'handbook' style to tackle his subject. Like the best examples of this approach, the book pares down a wealth of material to the essential information the reader wants to know. In this case the author addresses the common questions and anxieties that face parents and professionals in dealing with bereaved children.

Dyregrov's writing is clear in its description, and explicit in its advice, and demonstrates that the daunting task of helping a child through grief is both manageable and rewarding.

He is not shy to tell you what to do but is sensitive to the worries and reservations that adults have in communicating with children about death—in particular that their intervention may cause more harm than good. For example, chapter six is devoted to decisions about the involvement of children in the rituals following death—funerals, viewing the body, etc.—issues that can prove particularly stressful for adults. I found the author's advice was commonsense and persuasive. He recognises the beliefs and prejudices that all of us carry regarding the role of children in 'adult' events and sensibly gives equal space to considering how parents can include their children at these occasions and to advising those parents who clearly feel they cannot involve them.

The book covers all aspects of children's experience of bereavement, from the earliest reactions through to handling the news of the death at the child's school. I found the detailed account of grief reactions given at the start of the book a useful résumé, as Dyregrov is very good at linking our understanding of age and developmental factors in children to their needs in coping with loss.

For a short book—it is only 116 pages—the author still manages to find space to consider complex bereavement experiences, including children's responses to sudden death from suicide, sibling death, and when children are witness to the murder of a parent. He draws on a range of theoretical perspectives, eschews jargon and challenges the assumptions that we adults are apt to make about children and their responses to death.

I am full of praise for the thought that has been given to the preparation of this book but perplexed at the failure to include an index. The whole book lends itself towards dipping back into the text for information as and when you need it. Not making this as easy as possible seems a puzzling oversight.

This book will, I am sure, become required reading for all those touched by the care of bereaved children.

DAVID PENTECOST
Family Therapist, U.K.

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