

# Crisis Intervention following the Loss of an Infant Child

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## Introduction

Research reports indicate that the loss of a child precipitates a disruptive and severe grief and mourning response that can cause serious emotional and social problems, even years following the event<sup>1</sup>. Pathological grief reactions occur in 23 to 33 per cent of the parents<sup>2-4</sup>. This paper describes a support programme developed at the Department of Pediatrics, University of Bergen, Norway using preventive grief crisis intervention following the death of a child. The programme included families of children who died at the Neonatal Intensive Care Unit, families who experienced a Sudden Infant Death Syndrome (SIDS), and families who lost children in accidents (mostly older children).

## Grief crisis intervention: objectives

Among the objectives of the grief crisis intervention were: (a) to offer human support and comfort (b) to promote the mourning process and prevent pathological grief (c) to prepare the parents for expected reactions and problems (d) to help mobilise social support resources, and (e) to stimulate family communication and cohesion.

As we gained knowledge from the intervention process, we changed detrimental hospital procedures, set up grief groups and conducted educational workshops and seminars for health professionals and community caregivers. These efforts were aimed at creating a better recovery environment for the bereaved families.

We tried to individualise our approach to each family and be sensitive to their needs. An outline of our general approach, and specific interventions aimed at surviving siblings, have been presented elsewhere<sup>5-7</sup>. In many respects our crisis intervention was similar to others<sup>8-10</sup>.

## Anticipated loss

When the loss of an infant was anticipated the psychologist made early contact with the family, and emphasis was placed on creating a supportive environment on the ward, where both parents and siblings were encouraged to visit, see and touch the infant. The family was given the option of a

separate room, and the effects of a technological environment was alleviated by introducing toys, pictures, etc. The family were offered support throughout the dying process, and the nurses were encouraged to handle the dead baby with great care and respect.

Frequent family conferences were held when the child's medical condition deteriorated, and parents were encouraged to discuss their reactions, thoughts and feelings about the child's situation and the anticipated death. The needs of other children in the family were addressed. Being able to stay with their child as much as possible seemed extremely important to most families (cf. Miles & Carter<sup>11</sup>), and parents were motivated to spend time together with the child whenever possible. When parents subjected themselves to intolerable doses of stress, they were advised about taking care of themselves and their children.

## Immediate follow-up

When a child died, the intervention varied according to the type of death. Great care was taken to try to make sure that the situation brought no further stresses to the parents. This meant focusing on details, e.g. the way the baby was dressed or held by the nurses, the time the parents were allowed to spend with the child, and the way questions were phrased. Furthermore, the physician talked with the parents in a comfortable and quiet room, avoiding interruptions. Gentle touching was often appropriate to convey empathy and support to parents. It was often felt that a gesture such as a gentle arm across the shoulder or holding a parent's hand was more needed than words, especially when entering the room with the dead baby.

When a death happened suddenly, we used an active outreach approach and contacted the family. We tried to create a warm and supportive atmosphere for our first meeting. The meeting room was quiet, the surroundings pleasant and the parents were offered tea or coffee. By these means we wanted to convey our wish to help and offer comfort, as well as to prevent the family suffering intrusive recollections of a cold and impersonal hospital system.

In the first session the psychologist conveyed some important information about normal shock reactions. Most parents experienced feelings of numbness and unreality, and needed gentle assurance that their apparent lack of feelings was normal. Without this assurance they often interpreted the absence of feelings as a sign of lack of love for the child, or as the first sign of going insane. They also needed to feel that everything possible had been done to save the child's life.

The first meeting also included a discussion of their other children's needs, when there were surviving children. Parents welcomed this opportunity to discuss how and when to inform siblings, and whether the siblings should see their dead baby brother or sister or attend the funeral. Most parents were very uncertain about these matters, and our knowledge about children's normal reactions to death at various ages was of great value to them.

Previously, bereaved parents had either had a short glimpse of their baby following a death, or none at all. With our programme, the psychologist encouraged parents to see their baby after the death. However, parents were always given time to become comfortable with the idea. They were told why they were being advised to see their baby and given time to reflect if they were reluctant. Parents (and siblings) were prepared for what they were going to see, as well as for reactions they might experience. Parents were supported if they declined to see the dead baby.

During the first meeting we found it was important to get both parents' accounts of how they experienced the situation. Letting both the mother and father tell their story was the first step towards making this a shared event, and helped to prevent a lack of understanding between the partners. As the father often feels excluded from the loss, the first session must signal clearly that he is part of the grieving process.

Parents were prepared for the fact that they might each experience a different grief reaction, and helped to understand these differences. They commented that this anticipatory guidance was especially helpful later on when difficulties arose.

Unfortunately there is a tendency in Norway to reduce the emotional distress of a funeral ceremony by having a ceremony where only the closest family members attend, and by stating in the death notice that no condolences are to be made. We advised against this practice by stressing that it prevented the grieving family from meeting sources of social support and that it fostered an escape from the emotional pain that needed to be confronted. We described the funeral rituals as painful but important and necessary milestones in the grief process.

#### Intermediate follow-up

Families varied in the amount of intervention required during the weeks following the loss. When possible a session was scheduled soon after the funeral, when the shock reaction often started to subside. However, due to the topography and extent of the region served by the programme, only a portion of the families received a minimum of one or two intervention sessions. Based on telephone reports and other feedback, it was intriguing how helpful many of the parents rated this limited number of follow-up sessions.

When the parents started to experience strong grief reactions, they were briefed on normal grief reactions. They were actively prepared for emotions and problems they would possibly face in the weeks that followed. Most parents had little knowledge of crisis reactions, and many normal reactions (e.g. irrational thoughts and 'hallucinations') were interpreted as signs of mental disease or serious disturbance. Psycho-educational counselling seemed to help parents cope with strong and unfamiliar emotions and thoughts, and to reduce their tendency to think that their reactions were abnormal or unique. In addition, parents were thus able to deal more effectively with their emotions and thoughts.

After the funeral, parents were better prepared to process information than immediately following the loss. This was the time when principal questions such as: Why did our baby die? Could the death have been prevented? Who is to blame? What did we do wrong? Can it happen again? needed to be addressed. Although these questions were difficult to answer,

the physician usually gave straightforward answers or reassurance. Most parents were eager to find out why the baby died. They had many questions for the physician, and many reported in detail what had happened again and again. As soon as the autopsy results were ready, these were presented to the parents.

There were almost always feelings of guilt and self-reproach (especially in SIDS parents) that needed to be worked through in

mented: 'I cannot console my husband—we suffer a common grief'. The sessions with the grief counsellor offered comfort and consolation, as well allowing for opening new ways of communicating within the family.

How mothers' and fathers' responses differ has already been documented<sup>13, 14</sup>. Mothers usually grieved more intensely and longer than fathers. It was also evident that mothers were more able to express their feelings. It was not un-

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some detail. Until these feelings were explored in depth, we tried to refrain from saying that there was nothing the parents could have done to prevent what happened. The parents' fantasies about the cause of death were often the real basis for their reactions. When these had been explored, parents could often let go of some of these feelings.

Much of the intervention process during this phase dealt with grasping the cognitive meaning of the event, and dealing with the unreality of the event. The experience of unreality was often prolonged when the baby had lived only a very short time, died at birth, or when the loss came without warning. In these instances making the unreal real was central to the intervention. Talking about memories, looking at pictures and visiting the graveyard brought reality closer and furthered the grief process. Making a memory book or a box containing different memories also proved helpful, especially when parents had had little opportunity for interaction with the baby prior to death.

Other frequent topics in these sessions were the parents' concern for the future, whether or not to return to work, relationships with their parents and relatives, aspects of chronic guilt, sadness, anxiety, and intrusive images. Parents with other children often found it difficult to cope with the conflicting demands of grieving and caring for children at the same time. Frequently other children became more demanding following the death, and parents needed practical advice on how to handle this situation.

When two spouses are simultaneously responding to the loss of a child it can be difficult for them to support each other<sup>12</sup>. The person one would normally turn to for support is also deeply affected by the loss. One mother com-

mon for one spouse to misinterpret the behaviour of the other, and for accusations which strained the marital relationship to increase. Sometimes the lack of synchronicity in grief influenced the intimacy of sexual contact and sexual interest, causing further problems for the relationship. In our anticipatory guidance we spent considerable time discussing such aspects with the parents, not only to provide them with information about expected reactions, but also to help them understand each other's different ways of feeling and showing grief.

If there was an emotional block, i.e. the impossibility of crying or the avoidance of stimuli that triggered memories of the child, active confrontation with the event through guided imagery was a helpful therapeutic approach.

By taking the parents back to the situation and making them actively confront the event, it was possible to help them through the emotional blockage. In addition to guided imagery, we used different behavioural confrontations about different aspects of the death (e.g. visiting the graveyard or the site of death, looking at linking objects, touching toys or clothes) to undo the emotional numbing, and to release inhibited emotions. Once emotional blocks had been breached by appropriate stimuli, time had to be allowed for these feelings to be worked through. Such 'provocative' grief therapy should not be done without more formal training in psychotherapeutic work<sup>15-17</sup>.

When the bereaved are unable to extricate themselves from the deceased, or when they totally fail to find the interaction with their environment rewarding, this is viewed as pathological grief<sup>18</sup>. In brief, the intervention for parents who evidenced chronic grief (most often mothers) consisted of facilitating the necessary detachment of

the parent from the deceased, of trying to get the mother (or father) to be active within their social environment, of stimulating emotional control, and of dealing with the deeper emotional meanings of the event. Sometimes the chronic grief originated from feelings of self-reproach and guilt. It was as though parents thought that their baby was watching them and would disapprove if they moved on in life.

### Isolation

Many couples signalled cries for help to their external support systems but received little response (cf. Helmuth and Steinitz<sup>19</sup>). A child's death arouses fear and feelings of vulnerability in others, and the more sudden and tragic the circumstances, the more isolated the family becomes from their social environment. Many parents had to provide support for their shocked network. This paradoxical situation sometimes exhausted the bereaved parents, and to guard against this they chose to isolate themselves from others.

Although well-intended, the efforts made by the parents' social network were not always experienced as helpful. Some 'help' actually added to the pain, as comments were felt to be unhelpful and hurtful. Close friends and family also had difficulties knowing how to help and what kind of intimacy the parents wanted following a death. Often they kept away in order not to add to the parents' pain. Although this was well meant, it often added to the parents' sense of loneliness or abandonment. Such issues were dealt with in the sessions with the counsellor. Regrettably parents' only support often seemed to be the sessions with the counsellor. The death of a child seemed such a tragic event that the family's network was unable to confront the pain it triggered over an extended period of time. Paradoxically, when the families' need for support was greatest, they received it least.

As we gained knowledge about network responses, it was possible to modify how the parents elicited support as well as to prepare them for the problems they were likely to meet. Thus parents were helped on how mentally to prepare for their interactions with close friends and relatives. Parents who took an active role in making a social recovery (e.g. specified their own needs) received more of the support and help they needed, when they needed it. The grief groups for parents which I initiated proved useful for many parents. As well as offering social support, these groups provided the parents

with a setting where they could compare their reactions with those of others and thus experience that their reactions were normal.

### Long-term follow-up

An important issue that arose during the long-term follow-ups was that of a new pregnancy. The majority of parents decided to conceive a new child within a year after their child's death. No specific time limit was set on when it was advisable to have another child, unless there were medical reasons for waiting. However, the parents were advised that they ought to be through the first intense grief period (often lasting from two to three months) before starting a new pregnancy.

A high level of anxiety surrounds a new pregnancy and following the delivery<sup>14, 20</sup>. Assistance for families expecting a new child consisted of psychotherapeutic help for anxiety (e.g. relaxation training, hypnosis, thought-stopping procedures), providing extra obstetric care, and extra paediatric check-ups following the birth. Parents' anxiety for their newborn child did not stop at birth, but continued after delivery. Often sessions were set up to focus on the parents' anxiety about their new child. Especially with SIDS parents, we observed extremely vigilant behaviour following the birth of a new child, with parents carefully watching the baby 24 hours a day and many choosing to use an apnoea monitor at home.

As a self-protective measure some parents did not dare to invest their feelings in their forthcoming baby until it was born. This also led them to doubt their ability to love the child when it was born, and here proper reassurance was needed. The programme therefore actively reached out to heighten the sensitivity of obstetric departments and private practitioners to these issues.

Parents gradually integrated the loss in their cognitive structures. Making sense of the event and finding some kind of meaning in misfortune were usually part of the cognitive working through of the loss<sup>21</sup>. In the follow-up session this cognitive integration was stimulated through discussions and interpretations.

Many parents continued to experience grief of various degrees for several years following the death. Anniversary dates were frequently difficult occasions, and periods of sadness and grief ensued. It was found helpful to schedule a follow-up meeting about 13 months after the death, to help with the thoughts and emotions triggered by the first anniversary.

### Discussion

Our programme included rapid outreach, a flexible approach, a focus on the present (although previous losses became a central part of the intervention for several parents), the availability of help, an open-door policy and the mobilisation of the victim's own resources. Through extensive use of anticipatory guidance and active reassurance and support, the counsellor was more active than in more traditional therapies. There was no refusal of the support offered by the programme, and this early intervention prevented the sedimentation of maladaptive response patterns. A basic premise in the clinical approach was that the programme dealt with normal persons facing abnormal events. Grief can, of course, be a precursor of illness if not properly dealt with, but it is not to be met by traditional psychiatric approaches.

In retrospect it was apparent that many parents, although they did not lack support resources, were reluctant to use them for fear of being a burden or of being rejected. The counselling sessions might have focused more time on this topic and thus helped parents to become more aware of the importance of support, and more skilled at eliciting effective response from others without being rejected.

The programme also underestimated the need for more extensive follow-up sessions for several of the families. Recovery time was often found to take much longer than the time period stipulated for crisis to be resolved (Caplan and Grunebaum mentioned four to six weeks<sup>22</sup>).

Dealing exclusively with crisis work in bereavement can be extremely stressful<sup>23</sup>. Empathy and caring for the bereaved requires that the counsellors are able to be in touch with their own feelings concerning loss (or potential losses). Grief crisis counsellors must be able to act as an advocate for the parents, be a social worker, offer a shoulder for the parents to cry on, and provide information and coping assistance to others.

Without a solid support system, a stable family situation, and the ability to express one's own reactions about the work, grief crisis intervention cannot be sustained for a long period of time. In my experience if counsellors are to be helpful they should be involved in a mixture of educational, clinical and research work, as well as being involved in non-crisis therapeutic work. A formal support systems for caregivers in this area is strongly recommended.

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## COURSES AND CONFERENCES

**Cruse—Bereavement Counselling Courses.** For details of Cruse Courses in the UK in Spring 1991, contact Cruse, 126 Sheen Road, Richmond, Surrey TW9 1UR (081-940 4818).

**Good Grief Training Courses** to complement the Good Grief Packs for schools and colleges are available through the author, Barbara Ward, 081-560 6385. (Packs available from Cruse, 126 Sheen Road, Richmond, Surrey TW9 1UR (081-940 4818).)

**Hospice: Building Bridges.** 6th International Conference of St. Christopher's Hospice, 20-24 May 1991. London. Details: Avril Jackson, St. Christopher's Hospice, 51 Lawrie Park Road, Sydenham, London SE26 6DZ.

**Lisa Sainsbury Foundation** residential workshops for GPs and district nurses. Topics include communication skills, loss and bereavement. 1991 dates and details from The Director, The Lisa Sainsbury Foundation, 8-10 Crown Hill, Croydon CR10 1RY (081-686 8808).

**Loss and the Ill-treated Child.** Includes Dr. Emanuel Lewis on The Ill-treated Replacement Child, and The Impact of Adoption on a Family with a History of Bereavement and Loss. 17 May 1991. London. Details from Training Office, The Tavistock Clinic, 120 Belsize Lane, London NW3 5BA, 071-435 7111.

# Feelings on the Loss of a Son after Many Years of Illness

Courage sometimes I do not have, I feel it ebbing away, failing me as it did whenever Oli was really ill and a trembling fear overtook me. I was so afraid he would die. Sometimes at home on dialysis when something went wrong, I had to muster all my strength and courage to do the right thing calmly and well; I was very afraid then. On occasions in the hospital when he was near to death I could hardly bear it, the prospect of losing him was unthinkable, terrifying; I had to try to be courageous then. The joy that followed on seeing that for the time being the crisis had passed was unparalleled—we could carry on, death was behind us, excluded from our minds. On we went, tackling his life-threatening illness by stimulating his enthusiasm for new experiences and knowledge, and, of course, by everyday love and care. Being aware that his end could come at any time was ever present, but how squarely did we face it? I suppose it came into my mind every day but it was immediately banished, too terrible to contemplate. Oli was so deeply enmeshed in my life that I could not try to imagine what the loss would be like.

Although he had been ill since infancy, the last six years became a pattern of crisis after crisis: haemorrhaging, major operations, intensive care, coma, an unsuccessful transplant and recovery, all borne with incredible courage by him. He inspired many people with his ability to retain an amazing zest for life and with his lively sense of humour in spite of pain, dialysis and illness. I was proud of him and somehow felt privileged to care for a person with so much to give.

When the last illness came, two months off his 19th birthday, he was still reluctantly dialysing and was weak and ex-

hausted. Daily I put more and more of my energy into his life. The zest was still there but flickering. He had struggled enough, I was shocked and anguished by the speed with which he had finally taken a turn for the worse, I knew that this time it was to be. The awful inevitability was upon us. The grief was appalling but he was deeply unconscious and knew nothing of our great sorrow which he would have found terrible to bear.

He had shown great fortitude in his short life, knowing that it would be a short one. His patience and mine combined, worked well; when one of us had it, we had enough for both and usually we both had it most of the time. Fulfilment came to him in his creativity, painting, woodwork and photography during illness and during better times. Peace was at his end, complete peace, a departure from pain and suffering.

Now we are on our own the loss is immeasurable. There is a huge hole in my life that was occupied by the care and cherishing of the child whom I tried to compensate for having been born with a crushing hereditary disease. Time hasn't yet worked the wonders that I am told it will, and I must use again the patience needed so often before. Peace comes especially on reflection of Oli's life. He gave others in trouble encouragement and understanding, his life was certainly not in vain, but the time had come for him to go. His life was complete, his work done. I know that we will recover in the main, never completely. A scar will stay, a wound so deep must leave a scar. For his sake and for the very love of life we will move on, applying the same measures given to his care to our own lives, ensuring as good a recovery as possible.

BRENDA BRIDGEMAN

# Viewing the Body after Death

Should bereaved relatives be advised to see the body after death? Little evidence is yet available but there are indications that viewing the body may help grieving to proceed, and that not being able to see the body may increase the difficulties the bereaved experience afterwards. Appropriate preparation of the bereaved for what they are about to see appears to be important. Further research is needed and some authorities consider that no dogmatic recommendation can be made that the body should always be viewed.

These issues are discussed in three recent papers<sup>1-3</sup>. Fiona Cathcart, a psychologist, in an editorial in the *British Medical Journal*, points out that after a stillbirth or perinatal death it is now normal practice in the United Kingdom for parents to be shown and to hold the baby<sup>1</sup>. This is often so even if the baby is disfigured, as the parents' fantasy may otherwise be of something far worse than the reality. Photographs of the baby are often taken and kept so that parents who are too upset to see the baby at the time can see them later if they wish.

In adult deaths, especially violent deaths where there has been disfigurement or mutilation, the relatives are often advised not to see the body but to remember the person as he or she was in life. However, in a study of relatives of people killed in a rail disaster, Sing and Raphael<sup>4</sup> found that the majority of those who had chosen not to see the body regretted their decision 18 months later. Viewing the body is also believed to help by giving the bereaved evidence that the dead are indeed dead, giving a physical image of death and allowing the bereaved the opportunity to say goodbye.

Cathcart concludes that viewing the body does seem to help grieving and that photographs should be taken and kept. But she warns that people must be carefully prepared beforehand, as the experience might precipitate post-traumatic stress disorder. It may also be that those who choose to see the body are different in their personalities and ability to cope from those who decline.

Peter Hodgkinson and Michael Stewart (United Kingdom), a psychologist and social worker, discuss the significance of the body in grieving, particularly in the context of reactions after a disaster<sup>2</sup>. They consider that for some it is an important but transitory image which allows the bereaved to internalise the concept that the familiar, palpably alive, physical presence of the person no longer exists in the external world and that memories are all that remain. They believe this is even more important after sudden deaths where there was no preparation.

What if the body is not recovered or is so badly mutilated as to be virtually unrecognisable? Hodgkinson and Stewart, who have experience of working with bereaved people after the Zeebrugge and Bradford Fire disasters, observe that in such circumstances not being able to view the body can lead the bereaved to doubt that the person they have lost is dead.

Modern scientific methods allow a person to be identified even from the scantiest of remains, but though the bereaved believe what the experts tell them they find it hard to accept at an emotional level. For many, a process develops which Hodgkinson and Stewart tentatively call 'Questioning Syndrome'. The bereaved person develops a set of thoughts that the