EDITORIAL

Two accounts (the first of which we publish anonymously) of the effects of losses of different kinds, are vivid personal testimonies to the enduring and profound effects of grief on human functioning. The widowed mother's suffering which led to depressive illness so severe that admission to mental hospital was needed, led also to losses for her infant daughter, the effects of which may not yet be fully manifested. The author pays tribute to the excellent care she received in hospital from nurses and doctors, but less thought appears to have been given by the mother's professional carers to how the baby's losses could be minimised and her mental health safeguarded. The account by an Irish university lecturer of the loss of her baby through her decision to have her new-born daughter placed for adoption tells us poignantly of the continuing pain of such a decision, and has much to teach those who are involved in organising and providing post-adoption counselling services.

Berry's account of how the parents helped the children through the illness and death of their infant brother is a good example of preventative work with children, and we reprint it here as an example of what parents can do to help their children even when they themselves are grief-stricken.

The papers by Blackburn and Lecky are good examples of small research studies designed to further our understanding of teachers' attitudes to bereavement, bereaved children and death education respectively. We publish them to encourage teachers to feel more confident in approaching the subject of death with their pupils and to encourage others to embark on circumscribed, manageable studies which give us useful information. Often our readers tell us that they switch off at the mention of the word 'research' and we hope that these studies will demonstrate that research can be useful and accessible to those who care for bereaved children.

Depressive Illness after Bereavement: a personal account

Whenever I read someone's personal account of their experience of bereavement, I am amazed and impressed by the clarity with which they seem able to recall events and, more particularly, their progress through the various stages of grief.

It was not like that at all for me. At best I can only recall a jumbled mass of feelings and events, which seemed at the time hardly to belong to me at all. I used to read books about grief, in the hope of understanding what was happening to me, but I couldn't identify with them. I used to think: 'There must be something wrong with me. I haven't experienced any of this.' Now, five years later, I still haven't experienced any outgoing anger, any upset, nor indeed the letting go and acceptance of the continuation of my new life. I did, however, experience an inner turmoil which was so overwhelming, so threatening and so totally confusing, that I was incapable of dealing with it other than by pushing it away and denying any real feeling at all. I was unable to share any of it, for fear of losing control completely.

Immediately after the death

I remember in detail events that occurred during the 48 hours preceding my husband's untimely death as if it were only yesterday, but, by contrast, I have mostly only vague memories, shrouded in fog, of events following his death. However, I can recall certain things very vividly. Three police officers brought the news that my husband had committed suicide by throwing himself 80ft from the top floor of the Polytechnic where he was a lecturer. It was during the lunch hour, when the campus was always very busy. I can remember feeling sorry for the students who unfortunately had to witness such a dreadful thing.

The police sergeant commented that I didn't seem surprised or shocked at the news. Surprised I was not, for I had been feeling very uneasy and restless for 48 hours, with an unspoken, vague, helpless knowledge of something dreadful being about to happen to my husband. Shocked I certainly was, so much so that I felt stunned by a terrible blow deep down inside myself, whilst remaining terribly calm on the outside. I desperately needed to hold my 18-month-old daughter, who equally desperately wanted to come to me, to be cuddled and made to feel safe from these strange visitors, but the young policewoman, lacking the wisdom of motherhood, thought she was being helpful by keeping her away from me. I was unable to communicate any of what I was feeling though, so I just allowed her to continue to battle against my strong-willed, unhappy toddler.

The next thing I remember with clarity is the arrival of my parents that same afternoon. My mother came in, shaking more than ever from her Parkinson's disease. She put her arm around me, but withdrew it quickly because it made us both feel so uncomfortable: I had never turned to her for comfort, physical or otherwise, for she was unable to provide it. She cried and I immediately reacted in the familiar way that I had known since childhood, by controlling my own feelings of unhappiness in order to be able to comfort and placate her. My father made an awkward attempt at words of comfort, but we had not communicated for so long that it was pointless. Any attempt by him at closeness would have been completely out of place. I did not look to him for comfort—I had given up trying long ago. Therefore, I was relieved to find him quickly heading towards Katie, and concentrating on the one small person to whom he could relate without too much difficulty.

Somehow my parents came and went and Ian's parents arrived. I don't remember much about that, except that I was relieved to see his mother. His father, however, was frequently very tearful; he had had a stroke only two days before Ian's death and it was all too much for him. I couldn't cope with seeing him so upset and my own feelings became even more deeply internalised and well hidden away as a result. At some point he must have taken two photos of Katie at that time. I was not aware of her, but I hate those photos. If anyone is in any doubt about the fact that children, even young children, grieve, they should see the photographs of my daughter in a state of utter misery and confusion!

By the time I was allowed to go and see Ian at the funeral parlour he had been so well 'put together'

with make-up etc. that I couldn't make the link between what I had been told about his rather violent death, and the figure that was lying so peacefully. Only his nails and fingers were black. I was swept away, very hurriedly, by a well-meaning relative before I had had enough time to sort things out in my mind. I needed more time at that point. Apparently, I was very difficult to deal with during the funeral and even more so during the cremation. I hadn't realised that I felt so strongly against cremation —no-one close to me had ever been cremated before.

Eventually my in-laws went home and I was alone. During the next few months I became very depressed. I was unaware of Katie. I have no memory of her at that time, though I seem to have automatically taken good care of her. I was lost in another world. I continually watched for Ian and frequently mistook other people for him. I became convinced that he was alive and 'around', perhaps living with someone else. That feeling of him being alive and living elsewhere is still with me at times, even now, though I know realistically that it is an unreasonable denial of his death. I think it is related to a lack of understanding of the finality of death, a confusion which I can only possibly explain through the sudden disappearance, through death, of my much-loved grandma when I was only two years old.

The first year

So, during the first year, I became stuck in a kind of shock/denial stage of grief, with feelings so deeply internalised that I didn't believe I had any. Nothing, and no-one, could touch me, nothing could hurt me ever again! I was not lonely; I couldn't understand why people expected me to be; I was nothing. I was alone, isolated and safe, but extremely unhappy—I wanted to destroy myself. I felt guilty out of all proportion for not having managed Ian's manic depression better. I wanted to die and held some vague hope of being with him again, though this seemed an unlikely prospect.

Although that was such a black year for me, certain things are apparent which, with hindsight, helped me to survive the wilderness of my grief, helped me to stay alive. I wrote frequently to Ian—I wrote of my confusion, my depression, my guilt, my need to be with him at such a difficult time. Those letters to Ian provided an important outlet for expressing what was going on inside me. I still have them and cannot bring myself to destroy them. They are very repetitive, but so were the circular thoughts in my head.

Secondly, I kept a careful note in my diary of everyone who phoned, visited, invited me for tea, took Katie to the park or for a walk, and so on. I don't know why it should have been so important to me that I noted it all down—perhaps my links with life, humanity and reality were more precarious than I realised. Certain people were regular visitors and three in particular were definite lifelines for me: my general practitioner, the Revd. . . . and my neighbour, Margaret.

Interestingly, all three of these people said many times that I made them feel helpless and inadequate. I can only say, in response, that I valued their presence, not because of anything they could do or say, but because they made the effort to spend time with me regularly, in very difficult circumstances, for I was uncommunicative and instinctively pushed people away, though I didn't really want them to go. Many people thought that they were an intrusion on my privacy and went away, and many just could not cope with me and left me alone, but these three people refused to give up. They were calm, caring, good-natured, secure characters who didn't demand anything from me emotionally, but accepted me as I was. I took what little strength I had from them.

Finally, I became preoccupied with what I was eating and with my weight, which fell dramatically. I kept a careful note of everything I ate and drank and of how many calories I consumed. I tried to eat less than 300 calories a day, recording such things as a quarter of a banana, a finger of toast, a quarter of a Weetabix and so on. If I consumed 500 calories or more, I felt terribly guilty and was overwhelmed by a real sense of failure. I would record scathing comments about myself, with exclamation marks, and determine to control myself better the next day. I can't remember how or when it all started, but five years later I have still not overcome this problem, though my weight is now more acceptable to other people, if not to me.

Going into a psychiatric hospital

Eventually I was admitted to a mental hospital. I don't remember very much of what was going on around me at that time. I had lost sight of any beginning or ending to my problems, but was overwhelmed by a sense of emptiness, guilt and worthlessness, with a tremendous confusion of thoughts which I could no longer communicate to anyone I had withdrawn into isolated safety, having built a solid wall around myself so strong that no-one could penetrate it and hurt me. I was desperately in need of help, but I was reluctant to accept that need and even hostile to the efforts that were made to help me. It was an automatic response, and so out of character, but I no longer had any sense of being. I was floating in space, rootless and lacking identity, so it didn't matter to me; nothing mattered to me. I no longer had any definite wish to die, but I had no interest in living either.

Hospitalisation brought its own problems. When I first arrived I was ready to run, to forget the whole idea, but the doctor who met me in Reception had a warmth and gentleness about her that struck a chord in me and made me hesitate. I was admitted 'for a few weeks' and was finally discharged approximately nine months later!

I was stubborn and uncooperative for much of the time. I had been 'sectioned'* after having taken an overdose of paracetomol while out of the hospital for a weekend, but I objected to having the responsibility and control of my destiny taken away from me. I reacted to the system in a childish way at times, which with hindsight makes me feel quite ashamed, but I was being asked so many questions about myself and about Ian at a time when I had no clear thoughts and was unable to verbalise the jumbled mass of overcrowded, fragmented thoughts that caused me so much mental fatigue. I needed to escape, to be by myself and to think in familiar isolation.

I needed to talk, but was reluctant to do so. I was frightened of losing control, of allowing someone else to know that I felt so desperately unhappy and that I was in pain. I wanted to share that pain, but I didn't think I could recover from

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the loss of control that threatened to overwhelm me—it seemed as if my life depended on it.

My daughter

My lengthy period of hospitalisation was further complicated by intense feelings of guilt because of my daughter's separation from me. At first my parents moved into my house in order to care for her, but they had great difficulty in coping with her wilfulness and with her energy! They imposed far more restrictions on her than I had done and she responded with a mixture of stubbornness, confusion and an iron determination to continue in a way with which she was familiar. Her behaviour was both extreme and erratic: she was either too well behaved, too helpful and too careful, or she was extremely disobedient and unmanageable. Clearly, she was very unhappy and insecure.

I have painful memories of the weekends when I was allowed home to be with Katie. My need to maintain contact with her was intense and she looked forward to my arrival with great excitement, but those short periods of contact were not good. She would cling to me from the moment of my arrival, demanding my constant attention, talking continuously and excitedly, desperately wanting my love and affection. But I had none to give. I was trying to cope with myself and could not accommodate the demands made on me by the one small person who gave me a reason to live. I didn't want to live, and resented the fact that I loved her so much! All too often she would be reduced to tears by my negative response to her efforts, or she would hide quietly away by herself, as if she had given up trying.

When my parents eventually decided that they could no longer cope with Katie, she went to stay with relatives in a nearby town. She was in a loving home, with parent figures who were kind and sensitive to her needs, but she refused to accept their love. She became obsessively independent, perhaps as a statement of her loyalty to me, but more particularly as a means of self-preservation. Her problems continued long after I had brought her home after being discharged from hospital. She had frequent, terrible nightmares and would kick me and punch me with her little fists tightly clenched, screaming at me wildly, her eyes wide open, whilst still apparently asleep. I was still depressed at that time and was exhausted by her unpredictable behaviour. I seemed to be constantly tired and reacted very badly towards her at times.

I worry about the long-term effects of the trauma of our separation; it is impossible to know the extent to which her personality has been shaped by it. At present she seems happily settled at home, is doing well academically at school, and has many friends. She seems to have forgotten what happened to her, but her sense of security remains very fragile.

Although the memories of Katie's difficulties remain clear in my mind, my memory of much of the time spent in hospital is very poor. However, I was always very much aware of the support of others, professionals and patients alike. The importance of feeling that I was acceptable to the doctors, and of trying to trust them, was of great significance. The importance, too, of the nursing staff and their attitude cannot be overemphasised. They played a big role in my recovery and their tolerance and consistent patience meant a great deal to me. Equally important was the patients' tolerance of one another's conditions and difficulties, as far as they were able. That, too, cannot be overemphasised when one is trying to recover a state of equilibrium and a sense of being.

Moving onwards

By the time I left hospital I had moved onwards through my grief to some extent. I could verbalise my problems to some degree and had begun to accept my new status as a widow and as a single parent, though there had still not been any release of feeling through tears or anger, and the lack of positive feelings about myself was still apparent. I could cope with practical difficulties, though without much real interest in life. Indeed, I have learnt to do many things which I would normally have left to my husband. I have also made new friends, whose interest and concern are very genuine.

For my part, I now find that I am more tolerant and compassionate towards other people. However, I am still very lacking in confidence, and lack any real sense of identity. Within a fairly short space of time I had lost my status as a full-time teacher and then as a wife; things had changed between myself and my family for various reasons, and I could no longer rely on the familiar daughter and sister status. There does not seem to have been anything to replace that loss, other than my continuing status as a mother. I still find that I have no sense of direction, which is very frustrating.

To accept life and become involved again after such trauma needs a tremendous amount of courage; there is a certain safety in depression and opting out, which is almost addictive. I have not yet found the necessary courage to leave all that behind me, to let Ian go, accept myself as I am and to risk becoming involved again, though the prospect of this seems less hopeless now than it did five years ago. Many small, almost imperceptible but significant improvements have taken place during that time, which have made me stronger and more likely to reach a point where I have the necessary courage to go forward and join in with life once again.

** Compulsorily admitted to a psychiatric hospital or unit for a limited period under the Mental Health Act.*

REVIEW

BRAVE HEART: THE DIARY OF A NINE YEAR OLD GIRL WHO REFUSED TO DIE
Joanne Gillespie. London: Century Hutchinson, 1980. £4.99 pb.

This 60 page book, written by a nine-year-old girl with a recurring brain tumour, has much to commend it. The introductory section is written by Joanne's mother and provides the reader with a parent's perspective on life-threatening illness in childhood. The remainder of the book is written and mainly illustrated by Joanne, who describes her experience of suffering from cancer and of the medical treatment she received.

This book will be of much value to children who have a life-threatening illness, to their parents and to professionals working with them. Joanne is able to remind professionals of how an ill child feels and of how honesty, kindness and maximal involvement of the child in their own treatment can help to reduce the child's distress.

Parents will be helped by recognising a child's ability to face her illness and maintain a positive attitude to life. Her statement (p. 52) that 'most grown-ups are afraid of cancer themselves and think that children will be even more frightened, so they don't tell them everything. I'm glad my mam and dad talked to me and explained as much as they could—I'm glad they were honest' may guide parents unsure how much to tell their child about the illness. Mrs Gillespie's experience and her ability to carry on will be a source of support to parents.

This book will be of great value to children themselves but their reading of it needs to be supervised and supported. Joanne's description of unpleasant procedures and her advice on how to minimise the discomfort—e.g. relaxation, distraction with music, visualisation—could be of much benefit to other children. She gives general advice too—the value of support groups, of positive thinking and the acceptability of crying. With this book, Joanne has achieved her aim of helping fellow sufferers.

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