

## EDITORIAL

The International Congress on Grief and Bereavement which took place in London last July was outstandingly successful. A major feature of the conference was the linking of personal experience with professional and voluntary activity. Researchers and the bereaved shared their unique experiences and benefited from each other. Over the next year, *Bereavement Care* will be publishing many of the papers.

We begin with the two personal accounts that moved the participants so deeply. Professor Sen asks whether a parent with a more distant relationship can help his children when the closer parent dies and finds that the development of the bond brings something positive when all else seems bleak. He is clear how important it is that we begin our counselling *before* someone dies.

Susan Hill is a novelist who spoke to us with great honesty and poignancy about three personal bereavements, all different, all painful and all teaching her and us something immensely important about living.

Also in this issue is a paper from one of the research workers who spoke at the Conference. Dr. Jones gives us an account of the value of the funeral of children in the mourning process and illustrates different facets of Australian culture.

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### Supplement to the International Conference on Grief and Bereavement in Contemporary Society, London 1988

Cruse—Bereavement Care has received many requests for the text of the plenary papers given at the International Conference on Grief and Bereavement in Contemporary Society held in London in July 1988.

Cruse is pleased to announce the proposed publication, later this year, of a Supplement to the International Conference. The Supplement is expected to include the Plenary Addresses by Dr. Colin Murray Parkes, Professor Peter Marris on Adult Grief and Bereavement, Professor Robert Pynoos on Children and Bereavement, and the First Professor Shamai Davidson Memorial Lecture delivered by Professor Gerald Caplan on Loss, Stress and Mental Health.

Anyone interested in reserving a copy of the Supplement should write to the **Publications Editor, Cruse—Bereavement Care, 126 Sheen Road, Richmond, Surrey TW9 1UR, England.** Bereavement Care subscribers will be able to purchase the Supplement at a special price. Further details will appear in the next issue.

# Bereavement and the Family: Some Personal Experiences

by

## Professor Amartya Sen

Lamont University Professor  
Harvard University

I feel very honoured by the invitation to speak to the International Conference on Grief and Bereavement in Contemporary Society. However, I also feel rather unequal to the task. Insofar as I have any qualification at all to say anything in this area, it arises from a terrible tragedy that hit my family and me a little over three years ago. My wife, Eva Colorni, died of cancer, at the age of 44, on the 3rd of July 1985. Our two children were then eight and ten. What had been an exceptionally happy family was suddenly plunged into misery, anguish, chaos and confusion.

The transformation was rapid. In the early days of December 1984 we were making plans for the Christmas vacation. The diagnosis confirming the worst possibility—a very extensive case of the most virulent type of stomach cancer—came through quite suddenly on 5th December. Eva was operated on three days later, with further bad news about the extent of spread, and the nearly terminal nature of the ailment. Despite the unfavourable odds that were explained to us, Eva was full of fighting spirit, and chose the route of radical confrontation rather than that of quiet submission. Aside from consulting the front-line experts for this kind of cancer in London, we also went, helped by friends, to seek the best advice we could get in the leading medical centres in the States and in Japan, particularly to find out whether anything experimental was showing promise. The only strategy for encountering the disease which seemed at all promising and which was, in fact, chosen, involved a lot of suffering, with only a slim chance of its working out, but Eva was still in great fighting spirit.



### Eva's fight and influence

Despite the medical judgments and probability statistics, there was not yet any sense of doom—not even great gloom—in the family. The children knew that cancer can be a fatal disease, but at that stage took their mother to be going through a bad patch rather than going irreversibly downhill. Even though I proceeded to read almost everything that can be read on the subject of stomach cancer, and knew fairly clearly where we stood, Eva's optimism was infectious, and I fluctuated between buoyant hope and reasoned despair from one day to another. Our friends and relations (Eva's sisters, parents and aunt, and others) were a source of great comfort and confidence. Looking back at the first four months of her life after her operation, I recollect a strange mixture of faith in the future along with a fundamental sense of fragility. But Eva's ability to fight on despite the physical suffering and well-grounded worries kept us all going smoothly, without laughter deserting the lives of the children.

And then matters took a terrible turn. With an early recurrence, followed by a couple more operations and the trying out of another experimental chemotherapy, Eva died, on the 3rd of July, after weeks of enormous suffering. It was a sunny, balmy afternoon, and her frail but brilliantly beautiful face was shining in the glowing light.

She clutched my hand as if this was another day when we could walk together in the meadows.

The children knew, when her condition changed for the worse in early May, that the bad patch was proving to be longer and nastier, and when they visited their mother in the hospital they could see how fast she was declining. But there was still a lot of smile when they talked, and I knew how hard Eva had to try to hide the extent of her suffering. She died a few hours after the children had visited her.

## The questions

The subject of this discussion is bereavement, i.e., what happened afterwards, rather than what occurred before. However, I have taken the liberty of beginning with the period of suffering and illness rather than with the bereavement as such, since I believe the pre-bereavement experiences had, in this case, a rather profound effect on the way the children in particular were able to cope with the disaster.

I cannot believe that merely re-collecting the devastation and grief that we as a family experienced can be of much interest to others—sympathetic though everyone must be. But perhaps it may be useful to try to put together some rather general thoughts that have occurred to me in encountering the problems that my family and I experienced. It is difficult to be sure that one family's experience can have relevance to another, since each ordeal is in some ways unique. But there can be some links, some elements of commonality, even in the most disparate experiences of bereavement and grief. I shall be concerned particularly with the nature of the relationship between the children and the surviving parent, and in particular between my children and myself in the ordeal we faced.

First, a little about our background and relationships. Eva, who taught economics at the City of London Polytechnic (and was very devoted to her work there), had been much more involved with the children than I had been before her illness manifested itself. We were a close-knit family, but the children had a much closer relationship with her than with me. This was perhaps partly because of the fact that I taught at Oxford and had to be away rather regularly from our home in London, but was mainly because Eva was overwhelmingly attached to the children and this aspect of her life fitted in nicely with her exceptionally caring and

warm nature. With her illness and then death, it was, as it were, the more 'distant' parent (rather than the 'closer' one) who was left to take care of the children. Among my hundreds of worries as Eva's illness progressed was the fear that this pre-existing asymmetry in our relationship with the children would make it particularly hard for me to be able to look after their psychological needs.

So one question to address—if I may slightly intellectualise a worry that was based on a terrible sense of personal inadequacy—is the precise relevance of the extent of the previous involvement of the surviving parent with the children. How much of a handicap was it that prior to the tragedy my relationship with the children, though warm and intimate, had been quite overshadowed by the nature and extent of Eva's involvement with them?

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A second question relates to the worry I had about whether to share harsh information and hard decision problems with the children. What to tell them (eg about Eva's illness and the prognosis), what decision-making role to give them (eg in determining whether we should move from London or not, and where we might go), and in general whether to emphasise authority, or to bank on co-operation.

Third, I felt initially confused about whether to encourage the children to remember Eva regularly and often, or whether to try to help them to avoid getting too obsessed with her memory. Eva remained tremendously alive in our existence, and the question was whether to adopt any conscious policy about cultivating or discouraging this constant presence, and if so, precisely what.

A final question was my worry about how much outside help to seek. Bereavement is a very private experience. It is a world of resilient emptiness—one that remains altogether deserted no matter how many people surround you. It was not clear to me how much others could possibly help in dealing with my grief, even though our friends, neighbours and relations were altogether marvellous in being supportive and making the logistic problems of our life much easier. I personally did not want to talk to anyone about the nature of the void

that surrounded me, because it seemed like an emptiness all my own, the nature of which others could not possibly understand no matter how close they tried to come. But what about help for the children? They did of course talk with me and also with the family friends about what had happened. Was that adequate, or did the children need therapy? Could I myself also benefit from professional help in dealing with my own problems and also in finding the best way to assist the children?

## Help and therapy

Let me look at these questions in turn, in the reverse order. As far as professional help was concerned, I had seen the merits as well as the limitations of this prior to our bereavement in the specific context of Eva's own worries and mental

agonies shortly before she died. She was looked after in hospital by a wonderful Registrar, Dr. Salim Malik, who not only worked extremely hard for Eva's physical well-being, but also for her mental peace. Dr. Malik decided at one stage that it might help Eva to talk to a specialist counsellor about her worries regarding the future of the children, in addition to whatever help she could possibly get regarding her own dreadful condition. A very helpful expert arrived and I knew that Eva found the conversation she had with her a source of considerable comfort.

Shortly afterwards, Eva had some supplementary questions which she wanted to put to the counsellor, and both Dr. Malik and I made great efforts to get her back for another session. That did not happen for over a couple of weeks because the expert was busy elsewhere, which probably shows the pressure under which the health service operates. But the effect was distressing for Eva, since she felt frustrated that the counselling could not continue and also came to question a little the caring interest of the counsellor she had found so comforting in the first meeting. By the time the counsellor returned, Eva was two days away from her death and heavily under sedation (although that conversation too was helpful to her).

My own attitude about seeking counselling remained sceptical—

not much helped by my frustration at Eva's own experience. We had the advantage of an outstanding general practitioner, Dr. Michael Modell, who had been immensely helpful to Eva in her period of tribulation and also to the rest of the family. We also had friends and relations with experience and wisdom. Be that as it may, I delayed seeking professional advice on child psychiatry until more than a year after Eva's death, and we were lucky enough to be sent to Dr. Dora Black, whose help was of the

conscious attempt to deal with problems that would arise after her own death. In particular, she had written a long letter addressed to the children to be given to them after her death. In this she discussed how things might seem for the children and how they might keep up a forward-looking attitude to life. It was a wonderful letter and proved to be deeply influential. Indeed, as I came back from the hospital in the early evening of the 3rd of July, just after Eva's death (I was accompanied by Eva's

discovered that I could not get them sufficiently engaged in new things unless I involved them in the planning of our lives. Luckily there was one particularly important decision in which I could get them to play a part: whether or not we should move from London and if so, where. Eva had thought that going to America might be a good thing for us after she died, but not for a couple of years. That time scale, which seemed to me to be just right, gave us the time to become involved in deciding whether and where to go.

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highest order and extremely valuable.

I am not certain now whether things might have been easier for the children or for me if we had received professional advice earlier. I am inclined to think they would, although by the time we sought help I had at least arrived at a fairly clear idea of which areas were going well and which seemed likely to cause problems. At the risk of oversimplification, it may be that the arrangement for psychiatric help and timely general counselling before bereavement may be of some importance in dealing with post-bereavement problems. This is where I did find a slight gap in the way things were organised. There is real help to be got here. The overwhelming majority of people in Britain—unlike those in the USA—don't go regularly to see their 'shrinks'. It is perhaps important to get pre-bereavement counselling in line with what would be needed after the bereavement. I don't know how adequately that usually happens now, and whether the resources allocated can cope with this need.

## Memory and communication

How actively should one keep the memories of the deceased parent alive? Here things turned out to be quite different from what I expected. My previous worries about how to deal with this dilemma proved much too theoretical. Even after her death, Eva remained a major ally in helping the children to face their problems. This was partly the result of her

sister), I read her letter to the children even as they were submerged in the terrible news. In fact, we read the letter together several times.

The letter had a remarkable effect in steadying them, and I imagine even made them feel her presence. It certainly made me feel that way; this was particularly plausible sitting in the living room Eva had fashioned, with the late-evening sunlight shining through the windows she had designed. It was her lasting voice in a world in which she was still alive.

Rather than being only an object of tragic memory, Eva continued to remain as a guiding spirit in the children's lives, and her foresight in seeing the usefulness of a communication of this kind made, I believe, a major difference. How constantly to remember her remained a question to be faced in the future, but in the early stages of our bereavement Eva's constant presence helped the children a great deal to think courageously and coherently about the future. I think we were very lucky that Eva had the wisdom and the strength, even in such terrible circumstances, to take such a far-reaching step—it had not been, of course, an easy letter for her to write.

## Involving the children in decisions

How far should the children be involved in decisions? One particular issue here was whether or not to treat them as adults. They were only eight and ten years old at the time of our bereavement but I soon

In particular, I made it a condition that any University offering me a job must provide me with the means to bring the children with me to see the campus, and as a result Indrani and Kabir came with me to visit a variety of Universities in the United States, including Princeton, Yale, Harvard, Texas, Stanford and Berkeley. We jointly gave marks to the different Universities, and it became a rather engaging exercise that integrally involved the future rather than harping only on the past. I believe the series of assessment exercises in which the children took part helped to give them a more forward-looking view of life. Indeed, I knew that things were going rather well when, one day, I overheard my son Kabir—then nine—explaining to someone on the phone: "Oh, Stanford? We are thinking about it." And we were indeed thinking about all the alternatives.

Maybe there are good clinical arguments against making bereaved children involved in momentous decisions—I don't know. But in our case it did seem to work out all right. It was like turning the page without forgetting the last one.

It seems to me that the emptiness created by a bereavement of this kind is never filled and indeed cannot be filled. Bereavement seems to leave unfillable voids in our lives. What happens with time is not that this empty world is filled, but that many other, new worlds emerge. Whenever one re-enters the old world in which the tragedy had occurred, one finds the void, the hollowness still intact—quite undiminished, but the new involvements make it possible for one to escape that permanent void much of the time.

## Antecedent relationships

Finally, what of the handicap of my not having as close a relationship with the children as Eva had? Looking back the handicap does not seem to have proved a

crippling one. This was partly because the nature of my relationship with the children underwent a radical change precisely as a result of the event itself. While Eva's death would have been less painful for her had she died of a heart attack rather than having to suffer months of being tormented by a merciless disease, it is also true that from the point of view of the children the slowness of the process gave them time to face the situation and also to get used to an arrangement whereby I had to take over Eva's role even before her death, when she was in the hospital and could still be seen and visited by the children. The process continued after her death, and at some stage, without my being self-consciously aware of what was happening, it became clear that I had become as

close to them as I fancy Eva had been.

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### **The experience of others**

I have tried to outline briefly

some of the worries and decision problems I had. I don't know what interest these things may have for others. Certainly, given the uniqueness of each bereavement, it is hard to draw anything like a "lesson" from one case for others. But bereavement not only tears one apart and takes one away from one's loved one; it also unites people with others who have had similar experiences.

There may not be much consolation there, but this uniting feature is also an important aspect of the experience of bereavement. The knowledge that others in similar situations to us were coping was certainly a source of some confidence in our case. Comfort, like tribulations, seem to come from diverse sources.

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# Personal Experiences of Bereavement

by

**Susan Hill**

Novelist

My only qualification for talking to you today is that I have suffered various bereavements in the course of my life, and occasionally written about them. But perhaps it is a good idea to bring everyone down to earth and back to basics. I have no claim to be any more of an expert than the rest of you—or come to that, any less. I am here not as a professional, not as an expert—simply as a human being. My personal experiences are no more remarkable than those of a thousand others.

But perhaps one of the differences is simply the way I have dealt with those experiences. I am and have always been a writer. I am first and foremost a novelist, a writer of imaginative fiction—stories in other words. I have never been an autobiographical novelist in the sense that I have simply taken chunks of my own life, raw, and set them down in fiction. Some people do write novels that way but with me the facts, the stories, the characters in my books have always been invented. It is the emotions that are authentic and important and of which I wish to speak. What I have felt, I have sooner or later given expression to

in the context of novels. Otherwise, I have dealt with grief and all the other emotions of bereavement by writing about my experiences in a more direct and non-fictional form. I have written articles and recently I have finished a whole book about my personal quest to have another child which includes the story of a miscarriages—an important form of bereavement by the way—as well as, at the heart of the book, an account of a neonatal death.

I consider myself to be extremely lucky in being a writer and so in having an important outlet for my pent up emotions. Grief needs expression above all—most people will find an outlet but many cannot do so. Being able to write has been my salvation—I think at one point, literally.

In the course of my experiences I have learnt many things mainly



about myself but also, a few lessons about other things. I believe very strongly that life is a continuing learning process, it is about growth and personal development—though often the process seems to be one or two steps forward, one step back! At the time bereavement seems to be a wholly negative experience. Death is a destruction, a dissolution of things, loss, nothing but minus on the account. It is only later, often years later, that you can take stock and realise then that as a result of it you have grown and learned, that there have been positive aspects, that you are more mature, further on in understanding, insight, sensitivity, as a result of that death.

### **Childhood days**

As a child I was very lucky. I rubbed shoulders with the business