

Reflections on the grief of parents

THE DISAPPEARANCE

Geneviève Jurgensen.

Adriana Hunter (translator)

London, UK: Flamingo/HarperCollins, 1999. 12.99 hb, £6.99 pb



Every so often we come across a story that deeply moves, confirms or even changes us. Geneviève Jurgensen's account of the sudden 'disappearance' of her two little girls in a car accident is one of these.

Jurgensen, herself a journalist, is writing 12 years after the event. The full horror of the accident and its aftermath gradually unfolds in a series of letters that she writes to a friend over a period of about two years. The memories are not sequential, but alternate between past and present as Jurgensen gradually allows herself to remember and re-experience the most painful moments and events. In turn, these memories evoke almost unbearably intense feelings in the reader. The movement from past to present and back again echoes the confusion which, one feels, must be a reflection of the writer's own state of mind in the face of such a tragedy. Jurgensen makes herself re-live the early days, months and years following her children's deaths. She poignantly describes how everyday events can suddenly take on a special significance, like her dead daughters' dental appointment which she keeps in their place, because she cannot face breaking the news over the 'phone.

I kept wondering: is the author trying to lay the ghost of the children who keep haunting her, or is she afraid of forgetting? Is it possible ever to make sense of these children's deaths, even after all these years? In essence, the book represents a desperate attempt to keep alive the memory of seven-year-old Mathilde and four-year-old Elise. Writing to someone who never actually knew them, Jurgensen's ardent wish is to

succeed in making them real: 'I would like it if just once when you are reading my letters, if just once you missed them'. She certainly succeeds in bringing them to life for me and, simultaneously, in making me remember the painful times following the death of my own daughter. However, though the book has particular relevance for those who have been bereaved of a child, it goes beyond personal experience by touching on universal themes of loss.

One of these universal themes is the feeling of regret, so commonly experienced after the death of a close, loved person. Jurgensen bitterly regrets not having had the courage to look at the dead bodies of her daughters after their accident – at the time she wanted to remember them whole and undamaged. I remembered my own regret, tinged with guilt, for not managing to stay and receive the condolences of all those mourners who attended our daughter's funeral, especially her classmates for whom the whole experience had been devastating. Another is the curious tendency of those around us to try to put the sufferer on a pedestal and praise them for their 'courage' for simply existing. I have noticed this also in cases of severe illness, or other tragedies. Is it some kind of unconscious insurance policy to protect the bystander from a similar fate? The message seems to be, 'You up there are so much more able than me to bear such a blow', which certainly has the effect of distancing the afflicted from the non-afflicted. Jurgensen describes another universal reaction and that is her surprise when she realises that others can still hurt her after having 'experienced the worst thing imaginable and thinking oneself "untouchable"'. I still remember vividly driving in my car a few weeks after Gaia died and thinking, 'That's it; nothing worse can happen, worry or hurt me' and feeling utterly perplexed to find myself getting anxious about being on time to meet my son from school.

A dilemma which never diminishes for parents who have lost a child is how to answer the dreaded question, 'How many children do you have?' Apparently innocent, it confronts us every time with the painful choice: to tell or not to tell. By telling, you have to prepare yourself for the reaction and a need to 'comfort' the questioner, which can feel like a devaluing of the death and its aftermath. By *not* telling, you deny the fact of that person ever having existed at all.

Like Jurgensen, I found the presence of another child in our lives kept me from total despair. Having worked with children professionally, I was only too aware of the implications of a death in the family for a young child, especially

one who had just stepped out into the world of school, and I felt guilt at my inability to soothe his pain. Jurgensen was fortunate that at the time she had a mentor, none other than Bruno Bettelheim, who became a lifeline for her and encouraged her *not* to feel guilty when, some months after the accident, she decided to become pregnant again. She asked him if it was right to give life to a child in those circumstances and Bettelheim answered: 'I am happy that you have done the only sensible thing you could: had a child. And I hope that you will have others as soon as possible. You will raise them in an atmosphere of great anxiety, which is absolutely normal and cannot be avoided.' Jurgensen tells us that, 'This last sentence had an instantaneous and definitive liberating effect on me.' Bettelheim's unconditional acceptance and affirmation of *her* is immensely encouraging. Too often, still, the advice of 'experts' is tinged with veiled criticism, giving credence to theoretical evidence over individual preference and appropriateness.

I found myself referring to Jurgensen's story, on a supervision course I was holding for counsellors recently, to challenge the still widely-held assumptions about past bereavements. When is a bereavement 'past'? What do we actually mean when we talk about 'ending' bereavement counselling? Surely we are not talking about the ending of the grieving process, but of the counselling relationship. All we can hope for as counsellors is that we leave people with a greater sense of their own resources to continue their lives, incorporating their loss. I find myself more and more wanting to challenge the often-heard lament by counsellors that a client 'is not ready', applied variously to either the starting or finishing of the 'counselling process', as if this process was a state of grace only meant for the enlightened. I feel that this is the wrong way round: it is us, the 'helpers' who are not ready and feel unable to support people adequately with the most intense and confusing aspects of grief, *even if it were desirable*.

The strength of this book is that it does not try to give answers; instead it describes one person's experience and her gradual emergence into full life again, encompassing both pain and joy. It is foremost a personal testament of love, a love which causes pain and which allows the author to live and give life to two more children. As counsellors, we need to read such books to be reminded that our role, so necessary at times, especially where support from friends and family is absent, is also limited. **BC**

Els Footman

Bereavement Counsellor and Trainer

BOOKS

LIFE, PSYCHOTHERAPY AND DEATH

The end of our exploring
Ann Orbach. London, UK: Jessica Kingsley, 1999. £15.95 pb

Ann Orbach is a practising psychotherapist and her book represents a thought-provoking examination of death. In an honest and open way, she confronts some of the issues surrounding this subject and helps us reconsider attitudes to death and dying, and the needs of those who may ask for our help. Looking at the problems faced by dying patients and their families, she considers the role of the therapist as helper in this situation.

Each chapter has an appeal of its own. I was particularly impressed with chapter two, which alerts us to the pragmatism of children and the joy of working with them. The examples given closely match my own experience, and pleasure, in this work. This is an area of concern for many therapists but the author underlines the straight-forward and honest approach of most children to the problems they face in their day-to-day lives, and confirms my belief that we need to help parents to trust their children's ability to handle bad news.

Other chapters continue with this helpful mix of experience and practical comment. Areas covered include AIDS, sudden death, slow death, the elderly, and the particularly challenging issue of those who only 'partly' live. Examples used here are those suffering from anorexia, bulimia and Alzheimer's disease, examined from the perspective of both patient and carers.

The final chapters take a more philosophical view, considering mourning, the role of dreaming and death itself. Yet here, again, the approach continues to be practical. We are reminded of the uniqueness of each death and the variety of funerals options, but are also led into a discussion on 'body, soul and spirit' along with consideration of how this may affect our own belief and practice.

This book is immensely readable though I dislike the term 'loss' used for death. Each chapter starts with appropriate quotations and could be read separately. This is a book for everyone working with dying patients and their relatives – not only to aid us in our work, but also to challenge our personal assumptions about death, dying and bereavement.

Ann Faulkner
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DEATH TALK
Conversations with children and families

Glenda Fredman. London, UK: Karnac Books, 1997. £14.95 pb

This book is particularly refreshing on two grounds. First, it is unusually humble in that the author quickly de-bunks any notion that it is possible to be an expert on bereavement. Second, it dares, in the opening chapter 'To talk or not to talk', to question whether bereavement counselling is always indicated. Fredman also addresses the professional conflict central to this work – namely the attempt to normalise the behaviour of the bereaved whilst at the same time being expected to treat it.

Initial chapters cover the assumptions behind referral: the meaning of the referral to families, and different concepts of death. The author then goes on to draw on her experiences as a clinical psychologist working in a paediatric setting and gives case examples of constructing stories co-operatively with families and 'commemorating' the person who has died. Finally, she also examines the issues that this sort of work raises within supervision. The appendices provide succinct summaries of the main theories of death and mourning, lists of books which will help children, and a useful cross-referencing section on eight illustrative case histories.

This is not so much a 'how-to' book but more an interesting philosophical reflection on clinical practice. It urges flexibility and eclecticism, suggesting that the role of the psychologist should be principally facilitative, concerned primarily with the task of helping children and families to make their own sense of what has happened and find ways to remember the dead person which they find most valid.

Gillian Colville
Consultant Clinical Psychologist

TRAUMATIC GRIEF
Diagnosis, treatment and prevention

Selby Jacobs. Philadelphia, USA: Brunner/Mazel, 1999. £45.00 hb, £20.00 pb

This is a timely contribution to the literature on responses to the death of a significant other. It presents in a concise and useful way some recent work on the definition of a new psychiatric disorder: 'traumatic grief'. This concept is intended to replace some previously existing and vaguely defined categories such as pathological

grief, morbid grief, atypical grief, and to introduce some scientific rigour into the definition of a disorder which can form the basis of further research.

The author presents arguments to support the validity of such a disorder, including a clear and thoughtful treatment of the problems associated with pathologising normal processes and the cultural context in which this disorder emerges. The book also provides the reader with useful information on differentiating traumatic grief from other disorders and comorbidity (associated disorders), a brief discussion of theory in relation to the aetiology (study of the origins) of the condition, a review of treatment efficacy, practical advice about treatment principles, and strategy for dealing with complex presentations.

Throughout the book the value the writer attributes to evidence-based practice is clear: statements and proposals are fully referenced and the writer takes pains to point out where research is lacking and where the science of the condition is only beginning. The book is illustrated by case examples which go some way to demonstrate the considerable clinical experience of the writer in this field, although I found the section on treatment of these cases to be too brief to contribute much to the understanding of the principles suggested.

The book seems to be particularly directed towards clinicians of all professional backgrounds who seek a scientific basis to their work on grief. It will also be extremely useful as an introductory resource for researchers in the field. **BC**

Ruth Williams
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RESOURCES

GOODBYE, GOD BLESS
A child's grief observed*

Karen Blumenfeld, Paula Trafford. (video) Manchester, UK: Planet Wild for BBC, 1998. On loan free, £25 deposit. Julie Stokes, Diana Crossley. (booklet) Manchester, UK: BBC1, 1998. £2.50 pb



Goodbye, God Bless is a video and accompanying booklet produced for BBC1's Everyman series and first televised in December 1998. In the eloquently produced video, we observe three different families recounting their memories, their experiences of grief and their journey through the Winston's Wish support programme. The emphasis is upon the child's view, in the context of their natural and daily environment. Throughout, Julie Stokes, Director of Winston's Wish, interjects her understanding of and insight into children's grief, and the care and sensitivity of the support programme's practical approach punctuates this video.

I was disappointed no reference was made to children's play as a form of communication, nor was particular emphasis placed upon the needs of the family. We observe children and parents being supported in separate groups and I was left wondering whether such separations were conducive to supporting the families.

The video is accompanied by an advisory booklet. It is both readable and user-friendly for parents, with in practical and informative advice. It is slightly let down by its design, and the section on 'When to seek professional advice' is somewhat vague. However, taken overall, this booklet is a useful addition, elaborating on important points raised in the video.

The video and booklet offer an insight into the world of bereaved young people – sadly, a rare opportunity. As an introduction to the plight of grieving children and as a national awareness-raising exercise, there is simply no comparison. I strongly recommend it.

ACTIVITY WORKSHEETS*

Winston's Wish. Gloucester, UK: 1999. 75p each, £8 for a set, including The Charter for Bereaved Children

These eight activity sheets are designed for parents, carers and professionals. Each describes an activity for helping bereaved children express their feelings and memories, such as 'Lighting a candle to remember' and 'Making a life book'. To meaningfully review them, I supervised their use within five families and summarise their comments here.

The activities were found to be most appropriate for children aged seven years and above; difficulties were experienced when using them with younger children. The sheets on 'Developing a memory store', 'Telling

*Available from Gloucestershire Royal Hospital, Great Western Road, Gloucestershire GL1 3NN.

RESOURCES

the story' and 'Making a first aid kit' were especially helpful, supportive and easy to use, but two of the other suggested activities, 'Making a jar of memories' (involving coloured salt) and 'Making a Christmas bauble', were regarded as difficult and impractical. All the families felt there should be more information on implementing the activities, the underlying theoretical rationale, and how to support children on a daily basis.

The sheets are colourful, user-friendly, well-designed and value for money, appropriate for not only parents and carers, but also for use by professionals supporting children. They are an important addition to my work at Zig Zag Children's Services, especially useful when building self-efficacy within families. I recommend them, but with the proviso that when offering them to families, adequate information and support must be carefully considered. **BC**

Robert Dighton

Co-ordinator/Play Therapist

ABSTRACTS

The myth of the replacement child: parents' stories and practices after perinatal death

Grout LA, Romanoff BD. *Death Studies* 2000; **24**(2): 93-113

Parents bereaved by perinatal death adapt to their loss in a variety of ways. If they have a subsequent child or children, their constructions of family life necessarily change. The subsequent child is thought to be at risk of psychopathology (the replacement child syndrome) if parents have not sufficiently grieved their losses. This article examines the stories told by such parents, with particular attention to how they represented the dead child and later children in the family structure.

Two different ways in which these parents maintained the connection with their dead child or children emerged: either they preserved the space in the family that the dead child would have occupied, or they created an ongoing relationship with the child for themselves and their subsequent children. The authors feel that there are multiple paths to parenting through bereavement, and that their study is only a beginning point in examining bereaved parents' ways of making meaning of their loss.

Developing services for bereaved children: a discussion of the theoretical and practical issues involved

Stokes J, Pennington J, Monroe B, Papadatou D, Relf M. *Mortality* 1999; **4**(3): 291-307

No one is likely to disagree with J.W. Worden's assertion that 'the death of a parent is one of the most fundamental losses a child can face' (*Children and Grief*, New York, USA: Guilford 1997). Yet every year many children and young people who are bereaved following the sudden death of their mother or father are given little or no support. Services to help them are beginning to develop in the UK, but with a minimum amount of national debate and no agreed standards or guidelines.

The authors of this interesting study believe that the way forward lies through the development of community-based children's services, which should be available for all bereaved children and young people and their families, providing resources, advice and support. They make a pertinent comment about a health culture which is able to react positively for all at the beginning of life while advocating the rationing of community services following the end of a life.

Bereaved children's questions to a doctor

Thompson F, Payne S. *Mortality* 2000; **5**(1): 74-96

This study was undertaken to determine: (a) what questions bereaved children would like to ask a doctor; (b) how a doctor responds to such questions; and (c) the factors that may influence this process. Written questions (121) were posed to a volunteer doctor by 99 children who took part in a grief support programme organised within the Gloucestershire area, England, for the purpose of helping to identify what issues may have been complicating the children's grief. Analysis of the questions showed that they fell into five categories relating to cause of death, life span, the role of doctors, the dead body and feelings of grief. A subsequent analysis of 35 more questions confirmed these findings. It emerged that the doctor employed three phases in his response - validation, reflection and description. One of the most revealing aspects of the investigation was the fact that the doctor needed above all to be sensitive to the children, and to realise what lay

behind many of their questions. The authors summarise the implications of their study with useful suggestions which should guide professional workers involved with bereaved children in helping them to understand and come to terms with their grief.

Adolescents and parental AIDS death: the role of social support

Dillon DH, Brassard MR. *Omega* 1999; **39**(3): 179-195

Adolescents who lose a parent to AIDS often have to deal with an aura of secrecy which hinders opportunities to receive social support and their ability to cope with their loss. A study was conducted to investigate the relationship between the degree of social support and the development of coping strategies, the participants being 15 males and five females between the ages of 11 and 17 years, one or both of whose parents had died from AIDS. Given the growing numbers of adolescents who suffer such a bereavement - and who, clearly, are a population at risk - and the unfavourable conditions which complicate their loss, it is likely that they do not receive adequate support. Yet the degree of help they are given has a major influence on the coping strategies they develop. Useful guidelines are provided for those who, in a professional or personal capacity, are involved with such bereaved adolescents.

The death of a parent in childhood: a family account

Elliott JL. *Illness, Crisis and Loss* 1999; **7**(4): 360-75

The feelings of three sisters, between the ages of 34 and 42, whose mother had died 28 years earlier are examined in this article. After such a lapse of time

the sisters still felt the sense of a gap or hole in their lives. What compounded their grief was that, following their father's example, they never discussed their loss with him, with one another, or with anyone else. From observation of the sisters' reactions, the author puts forward conclusions about what such a bereavement can mean for children in general - a change of roles, for example, and the loss of a major source of identity formation. The study focuses on two major issues: the experience of grief and the role of communication in the grief process. It suggests that openness about death is important, as well as recognition that grief is often a long-term process carrying on until adulthood.

Children, spirituality, and loss.

Cox GR. *Illness, Crisis and Loss* 2000; **8**(1): 60-70

Children face losses, and spirituality can be an important component in managing these bereavements. As each loss is unique, so are the ways of coping, even though children often imitate their parents' ways of grieving. This article presents the view that loss can be an opportunity for growth, wholeness, and holiness. Guidelines to help children in growing through their losses and in developing styles of healthy grieving are presented. The author, who is associate professor of sociology and associate director of the Center for Death Education and Bioethics at the University of Wisconsin, claims that spiritual journeys are paths that each must develop and follow through his or her life, since each journey is special and different. One cannot make the journey for children. At best, one can be a spiritual guide. **BC**

Sheila Hodges and John Bush

FORTHCOMING EVENTS

A listing of major national and international events directly related to bereavement

The Social Context of Death, Dying and Disposal. 5th International Conference. 7-10 September. London, UK. Speakers: Dame Cicely Saunders, Alice Lovell, Karen Haltunen, Vanessa Harding. Contact: Craig Spence, Goldsmith's College, London SE14 6NW. ☎ 020 7919 7035, fax 020 7919 7398, email: c.spence@gold.ac.uk.

Supporting You. Residential support and training courses for

volunteers or staff who work for a voluntary organisation helping grieving families. No charge except £25 for support materials. 12-14 September, 10-12 October, Chester; 1-3 November, Sheffield, UK. For further details and eligibility contact Carole Heeley, The Child Bereavement Trust, Brindley House, 4 Burkes Road, Beaconsfield, Bucks HP9 1PB, UK. ☎ 01494 678088, fax 01494 678765.