Personal Paper

Reflections on death in childhood

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During the past four years I have been involved in varying degrees in the death of about 70 people, most of them children and teenagers. Almost anything worth while that I have learnt about death, I have learnt from those young people and from those closest to them. Perhaps the most important thing has been the gradual recognition that however ill at ease and maladroit Western society is in the face of death, given permission and a loving, affirming environment, the individual will meet death with what I can describe only as a severe beauty.

Death is familiar to us in war, in holocaust, and in massive famine disasters, but we know it as remote control statistics. Death is no longer the familiar part of the domestic neighbourhood scene that it was 100 or even 50 years ago. Improved living conditions, health care, and highly developed skills in medicine and surgery, the breakdown of the extended family and the close knit local community, the tendency for the fatally ill, even the elderly, to be taken away to hospital or institution, all contribute to an unfamiliarity with death. Many people will reach middle age without ever having been in the presence of death and possibly without having attended a funeral.

The more sophisticated our society becomes and the more it pays homage to intellect and powers of reasoning the more ill at ease it is with death and that which lies beyond. Religion, belief in that which cannot be proved, and the readiness to allow ourselves to be led beyond our ken into the realms of mystery are things less and less to be trusted. Sometimes those who wield the greatest power and possess the greatest wealth are those who fare worst for here, finally, is something which neither money nor position can win back—life itself.

"Sparing" feelings

Our society does not handle death well. How often are the relatives asked to leave the hospital bedside when the patient takes a turn for the worse and the end seems perilously near and are only called back when it is all over? Perhaps it is because "heroic" measures are to be taken to forestall the end and the intention is to spare the relatives unnecessary distress, but it may be worth considering whether some relatives would rather be there even so; I do wonder who it is who is afraid and whose feelings we are trying to protect.

When it is all over we often seem to feel that now the best way to spare the feelings of the bereaved is to act with great haste. The funeral director is called in to remove the body as quickly as possible; the relatives are seen walking away down the hospital drive with a plastic bag or a suitcase containing the dead person's effects

within an hour or so of death. The doctor is asked to prescribe sedatives or hypnotics, and the funeral is planned on the first available day. The service itself is kept short and to the point and emotions are suppressed. Everyone is afraid of emotional behaviour, people stand at the ready in case the bereaved should lose all control and throw themselves into the grave after the coffin or tear apart the closed curtains in the crematorium. It is with a sense of relief that people repair to tea and sandwiches and the comfortable exchange of harmless small talk.

Some relatives and friends will be responsive to the need that the bereaved have of support and friendship over the next weeks but after that they will be few and far between. Then the general attitude prevails: best get back to normal and avoid all circumstances or conversations which serve as reminders of the one who has died. It is at this point that grief, which is a *natural response to loss*, is at risk of becoming suppressed and distorted to the extent that the natural response becomes a psychiatric disorder. I believe that the reason why so many bereaved people end up needing professional counselling or psychiatric treatment is that the rest of us are afraid. Face to face with grief we feel inadequate or embarrassed, we make ourselves scarce and fervently hope that there is an "expert" around to handle the situation. I hasten to add that this is not intended as a condemnation of the work of bereavement counsellors or psychiatrists. I readily accept that there may be factors in the life of the bereaved, quite apart from the reactions of others, which can benefit from professional expertise. Rather, I condemn a society which prefers to have such things dealt with at a safe distance, clinically and antiseptically, and seems to absolve itself from the responsibility for making itself available to be alongside and to stay alongside and to take on board some of the suffering and grief of others.

Trusting instinct

One beautiful autumn day a 10 month old baby boy died. We knew that he could not live very long but his actual death came on a day when he seemed particularly alert and happy. When he died his mother carried him into the garden, walked and sat with him in her arms for a couple of hours, often with one of us beside her, occasionally alone with him. She cried gently and talked to him. She remembered the day that he was born, also a beautiful sunny day; she talked of all the joy that he had brought into life and of the pain. Then, in her own time, she carried him back into their room and lay down with him still in her arms and slept for an hour. Then, and only then, was she ready to wash and dress him with very great love and care and without any sense of hurry. She chose the clothes he was to wear and the toys he was to have with him. She had already seen the small room, furnished much like a bedroom but able to be kept very cold, where he was to lie for the next few days. She carried him there. The little boy's mother and father visited him often in that small room, sometimes brushing his hair or rearranging his toys, sometimes lifting him out of his cot and sitting with him, uncurling his fingers and looking again at his hands, kissing him in the nape of his neck, lost in grief and in the wonder of the miracle that was their son. All they needed was our permission, spoken or unspoken, to do it their way, the way they knew instinctively, and our presence in the background and the knowledge that we felt pain and wonder too and were not afraid to show it.

As we cope with life so will we cope with death. Difficulties and conflict in

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relationships in the ordinary course of events may not disappear in the presence of death, indeed in the midst of distress they may be painfully exaggerated. It is not for those of us who are involved professionally to take sides but rather to believe the best of each individual and to try to support without discrimination. One relative may remain dry eyed and controlled throughout; the other hysterical and seemingly out of control. We have to accept both and not be thrown off balance by either. To whom is the hysterical reaction of a newly bereaved teenager a threat? In the privacy of a room can that young person not be allowed to lie down beside the dead brother or sister or hold the child or scream to God to bring this person he or she loves back to life again? And if that teenager asks to be left alone with the dead child for a time can we not take the risk? All this may be an essential part in the whole process of healing. Each member of the family, not just the chief mourner, has a right and a need to grieve and to express that grief in his or her own way.

Reality is gentler than fantasy

Children's fantasy and imagination are highly developed. I believe that the reality of seeing a dead brother or sister is easier to cope with and kinder to the child's sensitivities than the ordeal of experience by fantasy. On seeing her dead sister and showing no emotion and making no comment, it was several hours before a 6 year old said, "I thought when you were dead there was only your head. I thought all your skin peeled off." And then still later, "Where is she? How can she be in heaven when she's still in that little room?" I have found that the analogy of a shell or a chrysalis or a house can be useful. The important part, the living part, has gone on and this is all that is left behind. An exceptional 11 year old spoke of his body as a reflection. "It is how you recognise me for who I am. When I die I will leave my reflection behind but the real me won't die; when I die, the real me will go to that very special place." Many children have experienced the death of a pet. "When my dog died he left his skin behind," was the comment of a 7 year old. A 4 year old girl was trying to come to terms with the death of her 3 year old cousin. Helping her mother to clear the coal fire at home she said, "He's gone like the coal. Just the ashes left behind."

We must guard against using the adjective "peaceful" indiscriminately when describing death or the face of the child after death. If it is untrue it may distance us from the family who sense that this is one of the games that people play. It is true, however, that an hour or two after death relatives will often be comforted by the fact that the dead child does indeed look peaceful and even seems to smile. They may spend time with the child, greatly comforted, despite their grief, that "he looks so like himself." Then almost imperceptibly after two or three days a change comes about and the relatives will remark on how it's "not him any more," or on how "he's gone." Here nature itself takes its share in bringing about acceptance of what has happened and in carrying those who grieve a stage further on.

I hesitate to write about religion as a separate issue. Two things are clear to me. One is that mystery and a sense of awe surround death and whatever lies beyond it. The second is that an effect of love and grief exposed, the soul laid bare, is to bring forth reverence in the beholder. Here we find ourselves beyond the realms of reason crossing all barriers of different faiths. I would say that we share the experience of treading on holy ground. However much they may have ignored or scorned any kind of formal religion in the past, I do not think that there are many parents who do not wonder about the existence of a God when their child is dying. I have yet to meet a mother or father who has believed, at the moment of death, that their child ceased to exist. "She was so special and I loved her so much that there has to be a God to love her and a heaven where she can dance and play and be happy," said one young mother. Many parents will want someone to pray with them when their child is dying or after death. Speaking as a Christian, I know that there are many times when I can say only, "I do not know" in response to questions about the meaning of it all. Yet for myself I hold fast to the conviction that death is a beginning rather than an end.

One young mother who had experienced most kinds of deprivation and degradation in her own short life was resolved that her little daughter was going to have the life and the love that she herself had not known. The news that the baby girl had a rare, life threatening disease only strengthened that resolve and she cared for the child through the months of illness with singleminded devotion. Finally, she held her child through the last hours of life and we talked. The little girl breathed more and more slowly and then took one final breath. The mother looked up and said, "Is that it?" I nodded. "It's incredible," she said. "It's like giving birth again. After all the waiting and the pain, she's born. I've done it. She's there." This was the spontaneous reaction of someone with little education and no formal religion. After two or three minutes she handed me the child saying, "Is there some wine in the house? Everyone must drink to her. We must celebrate." Her grief in the following months has been as profound and as harrowing as anyone can experience but that does not in any way deny the rightness of her immediate, instinctive response at the moment of death. She dressed her daughter in a

red velvet dress that she had made for the occasion, painted her minute finger nails, and bedecked her with tiny jewels.

The days following death

The choice of clothes is intensely personal. For some it will be a traditional white shroud, for others a jogging suit or jeans, for yet others the clothes worn for First Communion or for parties. One little girl wore a ballet dress and new pink ballet shoes; a boy was dressed in his treasured Bat-man outfit. What matters is that it is right for this particular child and family and it can happen only if we provide an assumed permission to do it their way. I have a haunting memory of the distress a mother experienced when she was taken to see her child after he had died unexpectedly under anaesthetic. He was in a white shroud with his hair neatly brushed forward. She hardly recognised him. She longed for him to be in his jeans and sweat shirt with his hair rumpled back as it had always been. In all her grief she was grateful to the person who had taken such care to make him look nice, but he wasn't any longer her son.

Here I should add that although I write from the context of a children's hospice, many of "our" children die, quite rightly, in their own homes. Most of what I write is, I believe, equally possible and helpful there. I have been privileged to be with several families when their child died at home and the child has remained in his or her own bedroom until the day of the funeral. Nothing has been hurried, everything has been spontaneous and natural.

Some parents will want to register the death of their child themselves, others will be grateful to be relieved of the responsibility. For many the decision between burial and cremation is a painful one. Either alternative may seem intolerable to contemplate—the gradual decomposition of the body beneath the ground or the rapid consuming of the body by the flames. The thought of the child's hair and face being burnt is especially distressing for many parents. One mother asked to tour the crematorium before deciding. The director of the crematorium could not have been more helpful, showing us behind the scenes and explaining the whole process, answering all questions honestly and straightforwardly. Children who know that they are going to die will often express an opinion. One boy who had a progressively handicapping disease wanted his body cremated because, he said, it hadn't been much use to him in life. Another child wanted to be buried because she knew that her parents would want to visit her grave. For some of course religion will be the deciding factor.

Parents will often want to choose their child's coffin, and they must not be hurried in their choice or indeed in making any of the arrangements for their child. Toys or special treasures may be put in the coffin, though there will be others who take the view that such things are trivial and inappropriate. Letters or cards written to the child after death and placed in the coffin may be another step towards healing and wholeness for the one who writes. The planning of the funeral service is a personal thing and the parents' need is for someone who will give gentle guidance and perhaps the suggestion of some sort of framework allowing plenty of opportunity for the choice of music and words appropriate to their child. Just as the clothes the child wears are a matter of personal choice, so are the clothes worn by the bereaved at the funeral. We may be horrified at a young couple, whom we know to be very hard up financially, going out to buy new black outfits for their child's funeral. But for them this may be an integral part of their own instinctive ritual of grieving.

Many people say how much they dread the day of the funeral itself. In the event most will say that they found it a much more helpful experience than they had dared to hope. "Is it awful to say I enjoyed it?" asked one mother, "I didn't know how many people loved him and cared." Attendance at the funeral comes to be seen as a tribute. It is also a token of love and support to the parents and the family.

Forewarned is forearmed

I think it is helpful to warn parents or other newly bereaved people that other people's pious platitudes can be insensitive and hurtful; that however close the relationship between two people may be, they may grieve differently; and that the healing of grief is a very long, slow process. It is never complete; parents will never "get over" the death of their child.

The pious platitudes are seemingly endless. "Oh well, his sufferings are over now." "Poor little thing, it's a mercy really." "She is at peace." "Time will heal." And worse follows, "You're young enough to have another." "It's a good thing you've got the baby—that'll take your mind off it." If there is someone to laugh with about these remarks it helps, and so too does the recognition that people want to be helpful and they do mean well. It's just that

most people do feel inadequate and uncomfortable in the face of death and, if forced to say something, all sorts of things trip off the tongue.

Individuals grieve differently. For parents whose child has died there is the added complication that they are probably both worn down physically and emotionally, drained of the psychological resources they once had for meeting each other half way. One may grieve openly, the other finding it difficult to express grief. For both there will be an appalling vacuum at the centre of their lives, a sense of their arms being left empty. Half waking in the morning the reflex reaction may be to go and tend the sick child and then the nightmare of the realisation that there is no child to tend. A whole empty day stretches ahead and the one left at home may envy the one who goes out to work, or sometimes vice versa. It can be painful putting on a cheerful face at work. However sympathetic colleagues or work mates may be initially, the continuing grief becomes uncomfortable for them. Taking the surviving child to playgroup or school other parents tend to scatter as in the presence of one with a contagious disease. Sometimes the bereaved parent who takes most care with appearance or make up in a desperate attempt to "put a face on it" and keep going is the one who gets least sympathy and support because he or she seems to be coping.

Parents and siblings may manifest grief in different ways. The overt grief, the crying, the sorrow, the reminiscing is easier to take than the pettiness, the short temper, the clinging behaviour of the children, the rows seemingly over nothing. It needs someone to say, "It's all right. All these things are a very natural part of your grief. You haven't become a hateful person, neither has your husband, your wife, your child, your parent. Your anger against the doctor, the hospital, yourself, or God, is natural and safe. Give it time. Hang on somehow. A day will come when you will wake up and think, 'Yes, there is some point in being alive'." And it needs a friend or friends who will listen, however endlessly repetitious the conversation, who knows when to hug and when to stand back, who won't be offended by hurtful remarks, but will be alongside and readily available. Yet in all that I say about this and about all reactions and responses to death and bereavement there are exceptions. We each have to be sensitive and to recognise that we may not be the right person and may not be acceptable alongside, and that for some people grief is a private thing and must be respected as such.

For some a self help group such as Compassionate Friends or a support group such as Cruse may be useful. Those who have themselves experienced a similar type of bereavement can help as no one else can; the rest of us should guard against saying, "I know how you feel"—we don't.

Possessions and memories

Sorting out clothes, toys, and other possessions is very personal. Some people will feel instinctively that this should be done quickly. I think I would warn against a too ruthless clearing out. In the long term some of the child's personal things may be comforting rather than the reverse. For others the pain of sorting through possessions may be too painful to be tackled for many months. I think that they should be reassured that this is all right and that there is no hurry. There are extremes of course which might be judged as unhealthy—photographs quickly destroyed or put away and all evidence of the child removed or the bedroom preserved untouched as a sanctuary through many years. But on the whole, given permission and reassurance, the family will know instinctively what is best for them. In conversation a caring and thoughtful man expressed great concern for a neighbour of his. Some weeks previously the

neighbour's son had run across the road and been killed. Since the funeral the child's mother had taken to going to church each Sunday morning. Her husband took her to church by car and then walked through some woods by a river where he and his boy had often gone fishing. The man who was speaking to me was sure that this was unhealthy and needed to be discouraged. I hope I persuaded him that it was probably the healthiest thing that his friend could do—in the sense of health meaning making whole.

Favourite places, anniversaries, seasons with their associated flowers and smells, all these may be poignant reminders and need to be acknowledged. They are poignant not only for the parents—they may be just as painful for the surviving brother or sister. Other things hurt the surviving children too: the nagging feeling that the one who died was everyone's favourite and that they would have preferred it if you had died; the guilt of remembered remarks from the past like, "I wish you were dead," "I'll kill you," "Drop dead"; the fear that you might die too; the innocent question, "How many brothers and sisters have you?" And surrounding all this, parents who burst into tears unexpectedly or lose their temper unreasonably.

It does all take a very long time. More than one parent has said that they were grateful that we had given them early warning of this. Without such a warning they would have felt they were going out of their minds or abnormal—different from other people—when there seemed to be no light at the end of the tunnel well into the second year of bereavement. I have always been grateful to the father who told me that the second year was for him worse, if anything, than the first and that by the beginning of the third year he was just beginning to feel there was some point in living. I believe that the pain of bereavement is greatly intensified when society expects you to get over it quickly and you are left feeling stranded because you are a long way from complete recovery. After a gathering of bereaved families a mother who lost her baby daughter, her father, and her 5 year old son within four years of each other wrote, "If we go to any function people ask how many children we have; we have now learnt to say three. On Sunday it was so lovely to be able to say five. After all they were parts of our love and lives and with you they stay with us, outside they have to be locked away."

Conclusion

Saying to parents whose child has died, "You will get over it," is like saying, "One day it will seem as if he never existed." Nothing could be more hurtful. They don't want him written out of existence. But given time, given permission to be who they are, given reassurance to behave instinctively, given love and friendship, I believe that they will have the best chance to adjust to what has happened and grow towards healing and wholeness. Despite society's fear of death and ineptitude in the face of death, I believe that every individual has the potential within to meet death with a severe beauty which in no way denies grief. Being alongside such families you absorb some of their grief. But you also share some of the good things—learning to think of time in terms of depth rather than length; enjoying the swift growth of real friendship; bypassing the usual obstacles of class, creed, colour, age, education; having "all one's sensitivities heightened" as one father put it. And you begin to recognise and reverence the nobility and beauty in every man, woman, and child because tragedy lifts the mask of pretence and truth is revealed.

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