EDITORIAL

Many years ago I was asked by a friend with cancer, who had been told that he might not survive much longer, what he could do for his children. He so much wanted to leave them with something tangible to remember him. At the time they were very young, and I suggested that he write each of them a letter to be opened on their birthdays each year. In the letters he might remember himself at that age, reminisce about the things he enjoyed and some of the pains of being 5 or 15. He might make some guesses at how they were developing and give them some encouragement. He took my advice, but fortunately the children, now nearly grown up, have not had to read them as he made a good recovery and was able to be a father in real life to them. I was reminded of this when I read Lesley Elliott's article. She made videos, wrote books for each child, and tried to be honest with them.

Another article in this issue tackles ways of helping children to understand about death, and what the experience is of losing a sibling in a horrific accident. Madeleine's essay was written as a school exercise, and her teacher sent it to us with her permission. Would she have felt so betrayed if people had been more honest? Children, even more than adults, need help to grieve. But they rarely get it. Should we not be attempting to remedy this?

Dora Black
UK

Tomorrow, for me, is a luxury

Lesley Elliott, *BA*

In February this year my family and I went to Kenya. It was a very special holiday to celebrate the end of a 12-month battle. A year earlier, in February 1992, I had been told my breast lump was malignant. I had breast cancer. I was 33 years old. Until then I had been a full-time mum. My three children were quite small: Jack was five years old, Nancy four and Eve just 14 months. My husband, John, was a farmer and there seemed, until this time, nothing remarkable about us.

Following diagnosis I was immediately given a mastectomy. I spent a week in hospital, and some time recovering at home. During this period Grandma moved in and took over. Grandma was very much a short-term solution to what was going to be a long-term problem. I was to receive radiotherapy, which meant making four trips a week to Poole, 25 miles away, over five weeks. At the same time I was undergoing a six-month course of chemotherapy. It has to be said we struggled. Extra help around the house came in every form. Nannies, au pairs, family and friends. Our main concern was to disrupt the children as little as possible.

By August 1992 the chemotherapy was over. I was rather pallid and two-and-a-half stones heavier, but I had made it. Now I felt able to piece family life back together. While John was harvesting I took the children camping in Cornwall. Windblown and drenched, there was an overwhelming sense of normality; we were just like everybody else.

My mastectomy and I learnt to live together; my weight was beginning to drop and we decided to go to Africa as a treat. But while in Kenya I developed breathing problems. They did not spoil the holiday but there were underlying concerns for my health. Within 24 hours of arriving back in this country I was told I had secondary cancer of the lungs. The consultant told me how they would try to slow the cancers with a hormonal repressing treatment. But I realised that what he was really saying was that there was no cure. I was dying.

Nobody can say when I will die. We take each day as it comes. It seems something of a miracle that I have survived this long. Christmas shopping has been a bit of a surprise. Back in March I imagined it would be John's problem, yet here I am lugging about armfuls of gifts, with, it has to be said, more pleasure than I have experienced in years gone by. Tomorrow is a luxury; nowadays 'the future' is a period of time that doesn't include me. But it doesn't stop me planning ahead.

As parents, our priority was to organise our domestic regime. I insisted on a rigid routine that we could all depend on. We were not looking simply for employees, but for people with their feet firmly on the ground who would make a commitment to us as a family.

EDITOR'S NOTE

'What I do with them today is their memory of me tomorrow.' Lesley Elliott's children now have only their memories of their mother as she died eight months after she wrote this article, reprinted from *The Independent*. As Pynoos pointed out in his paper on the interaction of trauma and grief[1], children need to have their memories constructed for them if they are to carry a picture of a dead parent with them throughout life. I think readers will agree that this brave and moving account of how one mother did just that will act as a model for those working with dying parents to help them to leave behind the framework for lasting memories.

John rearranged his working day in order to join the children for breakfast and see them off to school. Our next-door neighbour comes in on weekdays to help wash and dress the children, then looks after Eve, sorts the washing, makes beds and generally runs the house. In the afternoons Eve goes to a childminder who lives 100 yards down the road. At 4pm, Sarah, our mother's help, arrives to manage tea, homework and bathing. This period is known as 'Happy Hour' due to the (absolutely normal) tiredness and grumpiness of little people at that time. Weekends we spend as a family. It's a struggle sometimes, but being just 'us' is worth the fatigue.

The routine has continued through numerous admissions to hospital for chest drains and operations. I have good days and bad days, but above all I keep busy.

The children know I'm dying. Jack asked me one Sunday lunchtime in a pub garden: 'If your breathing doesn't get much better, will you die, Mummy?' I told him that I thought I probably would. He told Nancy and for some time we talked a lot about it. Jack was anxious about his Daddy dying as well, and he wanted to know who would look after him and his sisters if they were orphaned. I said I felt sure Grandma and Grandad would bring them up. 'Don't be stupid,' said Jack, 'they're so old, they haven't got long to go!' He was also worried that I had a disease he could catch and would in turn die of. When we explained that this was not the case he seemed reassured. Finally, Jack wanted to know if, once I had died, Daddy would have to marry Sarah. I said I thought that highly unlikely as Sarah already had a boyfriend.

Being honest with the children has not been easy; one instinctively wants to protect them by lying and saying that things will get better. But this would betray their trust. It seems as long as they can believe 'they' will be all right, they can cope better than us adults. These days we rarely talk in depth about my death or my being ill; it is important to maximise every day. What I do with them today is their memory of me tomorrow.

A video camera was an absolute must. We record anything and everything. There is an exhaustive tape of us eating supper together, which may seem boring, but to my youngest daughter will be a priceless document of our everyday life together. It is hard to grasp that she will grow up with only the vaguest memory of me. We have taken endless photographs of me and the children, and I look at them and see all that my children will see of me in years to come.

My greatest investment has been the books I have written, one for each child. They describe my feelings for that child, the things we have shared, important events and unimportant occasions that were significant to me. The books are part diary and part fiction; each one contains stories about a family of children with no mother and a wonderful father. Through them I have tried to show how a mother's love does not cease with death.

I have used the books to invest in the future, help the children through the difficult times and alleviate any false fear or guilt. I have told them all that if Daddy marries again I would be very happy, because it would stop Daddy feeling lonely and it wouldn't in any way mean that Daddy had stopped loving me. I hope I have also given them the freedom to love a step-mother without feeling they have betrayed me.

The instinct to mother and protect is incredibly strong. One friend asked jokingly if perhaps I had filled the freezer to help my family through the early months of bereavement. The real joke is that I have. I have put my house in order, and will depart at my convenience.

Reference

1 Pynoos RS. Grief and trauma in children and adolescents. *Bereavement Care* 1993; **11**(1): 2–10.

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LETTERS TO THE EDITOR

Dear Editor

I am currently undertaking PhD research into the effects of bereavement in the first 18 years of life on spiritual and moral development – interpreting the adjectives 'spiritual' and 'moral' fairly broadly. For example, I am interested in whether or not any changes occur, either at the time of death or later, with regard to:

(a) religious thinking (acceptance, rejection or questioning of traditional creeds and beliefs);

(b) experiences of a sense of God or a divine power;

(c) attitudes and behaviour towards other people (improved, worsened or different in any other way);

(d) attitudes towards the world around (a greater or a lesser interest in animal and plant life, or the earth);

(e) attitudes and feelings about self, and her or his own life or life generally.

If any reader has material they are willing to share with me, I would like to assure them that it will be treated in complete confidence and, if included in my work, will be used in such a way that identification cannot be possible.

VALERIE CLARK
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Dear Editor

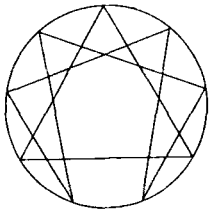
I have seen a number of cases of identical twin loss recently in which the surviving twin did not have the 'expected' reaction. In these cases there was no apparent grief and therefore the surviving twin saw no need for counselling, though their families were anxious for help.

I feel that this is an area worth looking at a little more closely and would be very grateful to hear from other counsellors or health visitors who have had any similar experiences with identical twins.

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PART-TIME SOCIAL WORKER



Working mainly with the hospice's bereavement support groups in North Gwent, North Gloucestershire and Herefordshire.

Pay & conditions to negotiate. Contact Dr Richard Lamerton