Softening the Blow: how one family coped with the death of their baby

Neil Berry

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In this article Neil Berry, a senior lecturer in clinical psychology, describes how he lost his five-and-a-half-week-old son. Here he explains how honesty with his children and the sharing of both sickness and bereavement made the loss easier to bear for the whole family.

Preparing Sam, 5, and Orla, 3, for the arrival of their baby brother was not difficult. They would regularly ask to feel the baby kicking and would even talk to him as their mother, Ita, lay in bed. Even when he was nearly two weeks late and Ita had been in hospital for several days, they were quite happy to accept that babies don't always come on time. On the evening in early September when Cian finally arrived, however, I realised that their easy acceptance of everything was about to be tested. I did not know how far.

Cian was delivered on a Sunday evening by Caesarean section because there was evidence of fetal distress . . .

When Cian was born, however, it became apparent that there were additional problems. He was a reasonable weight at six pounds three ounces and had a sweet face with pixie-like ears, but his feet and hands were clubbed and his ribcage was also slightly deformed. He had some difficulty with his breathing and was taken to the Neonatal Intensive Care Unit.

Once I had overcome my initial shock, I was faced with the task of breaking the news to Ita, the children and our families. I spoke briefly to the children on the phone, trying to sound as positive as possible but adding, 'He's a little bit poorly'. The next day I told them about their new baby brother and his crooked limbs. In response to their question 'Why?' I simply said that while babies are usually born fine, as they had been, a few are born poorly.

That day they were introduced to their new brother through the portholes in his incubator. Once they had overcome their initial shyness and come to terms with the strange machines that surrounded them, they talked to him and stroked him quite happily. As far as they were concerned they had a new baby brother.

[It was another 12 days before Neil and Ita Berry learned that Cian had Edwards' Syndrome and was likely to live only a few weeks. The specialist advised that medical intervention would at best extend his life only a little, so the Berrys asked if they could take him home.]

'You know Cian is very, very poorly,' we told the children as we drove away from the hospital. 'How poorly?' asked Sam. 'So poorly that he will die?' 'Yes,' we answered. Sam and Orla asked a few more questions, sounding intrigued rather than shocked, and then Sam asked: 'How does a speedometer work, Daddy?'

We did our best to live as normally as we could. Cian was taken out in the pram and went to the mother and toddler group with Ita and Orla. We kept Sam off school for the first week to make sure that he did not feel excluded. He and Orla spent their time at home much the same as usual, except that they would stop what they were doing from time to time to give Cian a cuddle or to help bath him or change his nappy.

Much to our surprise, there was never any indication of jealousy. They didn't seem to resent the amount of time and attention he received. At night, we all slept in the same room, partly because Granny and Grandad were staying, but also for emotional security and closeness. Sam and Orla slept in their bunk-beds and Ita and I on mattresses on the floor with Cian sleeping on a pillow between us.

Most of the time we realised that we had to prepare ourselves and the children for Cian's death. We gently reminded them from time to time that he would die, but their response was often, 'I know that' or, 'You've already told us that.'

To a large extent we took our lead from them, answering their questions as honestly but as gently as we could. After Cian had been home with us for about 10 days, however, we all drove out to Blackburn's Pleasington Cemetery and Crematoria. Ita and I hoped that it would provide an opportunity for the children to ask questions. They did.

Responding to their questions on that bright afternoon, we told them that when someone dies and their body doesn't work any more, you can't keep it because it would go



bad and you can't just throw it away. 'So you can do two things,' we said. 'You can put it in a special fire that turns the body into a special smoke which goes up the chimney and mixes with the air, or you can put it into the ground so that it mixes with the earth and helps flowers to grow. Which do you think would be best: mixing with the air or with the earth?' Their reply was as matter-of-fact as if we'd asked them whether they wanted bread or toast for their tea: 'With the earth.'

[After three-and-a-half weeks at home, Cian developed a cold and, early one evening, simply stopped breathing as he lay on the changing mat in the front room with Ita, Sam and Orla.]

We called the children over: 'We think Cian may have died.' While Ita phoned for the doctor I made some attempts to resuscitate Cian but his body stayed perfectly still. Sam picked up his brother and carried him over to the settee where we all cuddled him. The doctor came and went. Then we all gave Cian a final bath and dressed him. The children played quite happily, returning to the front room every so often to cuddle him; Orla was delighted that she was able to carry her brother around without his protesting. It was a strange but peaceful evening.

We knew that Cian would not be buried for about five days, so the next day, a Friday, we all got in the car and drove him to the funeral home.

The wooden shelf was bedecked with soft toys, and a lovely little coffin was in the middle of the room. We tucked him in and left, sadly, for home.

We all visited Cian each day he was there. On Sunday, however, concerned that his appearance might change significantly before the burial on Wednesday, we kissed him goodbye and placed the lid on the coffin. The four of us then took a butterfly nut each and, once the children had finished arguing over which corner to take, we sealed it shut.

We had decided to bury Cian in a small babies' section at Pleasington Cemetery and, with the complete agreement of our families and friends, that only Ita and I and the two children would be there.

Wednesday arrived with a clear blue sky and warm sunshine. It was a spring-like day. We drove to a local flower shop and the four of us each selected flowers to place on Cian's grave. Then we collected Cian from the funeral home and drove to the cemetery with Ita and the children holding the coffin on their laps. Our two chosen priests —Catholic and Anglican—were waiting for us at the graveside and the manager of the funeral service stood by. We lowered Cian's coffin into the grave and the priests conducted a ceremony lasting only about five minutes. We finished, at Ita's request, by singing three verses from 'All Things Bright and Beautiful.' Then the grave was filled in and the four of us were left in the warm sunshine to tidy it at our leisure. Ita and I cried quietly, the children played and then we took photographs. It was a sad but lovely day.

Sam and Orla spent that day much as they might any other. They accepted Cian's death as another interesting event in a life full of fascinating things. The stillness and stiffness of his body, the cemetery and the burial held no fear for them. They participated fully in all aspects of Cian's life and death, and they now visit his grave with us quite happily—as long as it doesn't mean missing 'Tom and Jerry'.

There have been no delayed reactions in the months since he died. Notwithstanding our own uncertainties, we have emphasised to them that: 'It was only Cian's poorly body we buried—he is fine now and happy in heaven with Jesus.' They talk about him and look at photographs quite happily, showing full awareness that he is not coming back. 'Does Jesus have a pram?' Orla once asked. 'Of course he does!' we replied and she smiled, quite happy.

Ita and I have no doubt that for Sam, Orla and ourselves, "twas better to have loved and lost than never to have loved at all'. We are sure that we were right to involve the children as we did. Our actions were informed in part by psychological principles but were based above all on our understanding of our own children. We do not assume that what was right for us would necessarily be right for others; we would hope they would be allowed to find the right road for them, just as we were. We were able to enjoy the short time that Cian was with us. We hope, too, that his quality of life was such that 'twas better to have lived and lost than never to have lived at all.

Neil Berry is at the School of Psychology, Lancashire Polytechnic, Preston PR1 2TQ and is willing to be contacted about the article if anyone should wish to do so.

Bereaved Children and their Teachers

Margaret Blackburn, BA, MSc, DipEd

Psychological Counsellor, UK



There are few studies in which children's own responses to the loss of a parent through death form any part of the research. Where children's responses are noted, the sample has tended to be drawn from clinic populations of children already psychiatrically disturbed. Beverley Raphael (1982)[1] studied 'normal' children and included responses from the children themselves, but she commented on the difficulties of the research which included obstacles to contact with the families. 'Few (professionals) denied that bereaved children might have needs, but many showed a reluctance toward any method of finding out what those needs might be.'[1] The reluctance of the adult world to acknowledge the pain of grief in childhood is likely to have been a factor in the dearth of research involving 'normal' children's responses, and in obtaining accurate representations of their experience.

Children need to feel safe enough to broach their distress and sadness, but this opportunity is often not available to them in the family. The surviving parent may be unable to respond to the child's grief at this time because of his or her own distress, or the family as a whole may deny the possibility of grief in young children. It is clear from the literature that the presence and help of caring adults is paramount if the child is to survive the experience of the death of a parent without pathological outcome. But are the other adults in a child's life able to comprehend or facilitate the child's grief reactions?

In discussing the impact of the death of a parent on children aged 8-12 years, Raphael[2] comments on the importance of teachers to children in this age group. The study described below set out to discover the extent to which teachers are aware of the bereavement issues which are important to children who have lost a parent through death[3].

Aim and method

The experiment was designed to compare the way groups of children and teachers ranked seven categories of bereavement issues in terms of their importance to a bereaved child. The groups were: bereaved children; the teachers of those children; and a random sample of teachers working with children of comparable ages and schools.

Thirteen children took part, seven boys and six girls. All were past or present members of Maidstone 'Young Cruse' a special ongoing group run for children whose parents attend the Parents' Circle at the Maidstone branch of Cruse —Bereavement Care, a national