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A death in the family

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The ability to work through the grieving process by the open expression of grief makes for a healthy bereavement. For the spouse it reduces morbidity and mortality in this period; for the children it diminishes the risk of emotional disorder that may occur later in life when grieving over the death of a parent has not been satisfactorily completed. We describe a death which exemplifies an acceptance of dying and an open expression of grief which we believe was facilitated by the hospice philosophy and team approach to care.

Ani was of Samoan and Chinese descent. His wife Mahi is of Maori extraction. They have two children of whom Ani was very proud. Daughter Aira is outgoing and loves to dress up. Toby, the son, is a studious quiet child, academically brilliant and very helpful around the home.

At the age of 46 Ani developed abdominal cancer which was found at laparotomy to be extensive and inoperable and a colostomy was performed. As a result of the widespread retroperitoneal tumour he had gross swelling of the scrotum and both lower extremities and woody oedema of the anterior abdominal wall. The disease advanced rapidly with severe pain and Ani was admitted to the hospice for symptom control. At the earliest opportunity he elected to return home despite great and increasing disability. There he spent his remaining days

surrounded by his family.

We describe the circumstances surrounding his death, taking up the narrative in turn, describing events as we each witnessed them.

'I visited the home the night before Ani died. Mahi was looking very tired and seemed glad to see me. She was in need of reassurance because Ani had been breathless at times during the day. She wanted to know what she should do if it happened during the night and I told her "Just ring the hospice and somebody will come". When I left, the children Toby and Aira were settling down for the night in their sleeping bags on the floor beside Ani.'

'We visited again on the Saturday morning. Ani had slept in the lazy-boy chair as he had done since his return home. His feet were supported on the couch; his big swollen feet. Mahi was lying on the couch. She had slept there in a sleeping bag and was still there when we arrived. There they were all together, Ani, his

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wife and his children. That was when Ani spoke of a dream he had had that night. As we washed him and made him comfortable for the day he described his awful dream. He had dreamt of a room, in each corner of which there had been something. In one corner was a hook, in the second were blood-stained clothes and in the third corner was Mahi looking helpless. He felt as though he was being sucked out of that room, as though he was about to die and he was really frightened.'

On Saturday afternoon Tom, Mahi's father, rang the hospice in a distressed state to say that Ani was breathless and asked for a nurse to come quickly. He rang a second time within a short period, obviously very distraught and was reassured that a nurse was already on her way.

'When I arrived Tom was waiting at the gate looking agitated, and as I stepped from the car he said "He's gone, he's gone". We went into the house together and I saw that Ani had died. He looked very peaceful. I positioned Ani in the lazy-boy chair and placed an extra pillow under his head. He looked very comfortable. My thoughts turned to the family who were away at the time. Mahi had gone shopping with a friend and the children were at the pictures. We went outside to wait at the gate for Mahi's return. During this period Margaret (a hospice nurse) arrived and we all waited in the sunshine. It was difficult standing there anticipating what was going to happen. I was dreading the arrival of the family knowing it was going to be so distressing for them. I thought it would be appropriate for Tom to break the news to Mahi, so I asked him if he would like to.'

'Mahi, Aira and her friend finally arrived. Mahi had known something was wrong when she saw our two cars at the front of the house, and all of us gathered in the driveway. The news of Ani's death was broken and the whole family wept together. Mahi and her father walked up the driveway supporting each other and entered the house.'

'Mahi had been distraught at the news of Ani's death, but when she saw him it seemed to calm her, seeing him so peaceful, still there. Margaret was also feeling anxious, not having seen Ani, and was apprehensive about how the family would respond. As soon as she saw Ani sitting in the lazy-boy chair, just lying back as though

he was asleep it was a great relief, and she felt that this was how the family would see it also. And that was how it turned out.'

'Aira was a little frightened initially, but when she was told, "Look, he just looks as though he is asleep," she peeked around the corner and saw that he did indeed look very peaceful and was then able to go into the room. She was cuddled by her mother and together they wept. Aira cried for about an hour, she sobbed and sobbed, cuddled by her mother. After a time she was able to touch her father and gently stroke his hand, then his arm and then she put her head down on him. Intermittently she would lay her head on her father's chest and constantly she touched him.'

'Mahi's friend mentioned that Aira had made her father a lovely Father's Day gift. Aira said, "Dad won't be able to have his Father's Day present now," and Mahi answered "Yes he can have it, go and get it, Aira, show him what you have made." Aira went out and brought in a beautiful suede covered notebook with flowers and hearts on the cover. She had carefully made a card with her own words inside and she quietly placed her gift on Ani. She opened the card up and we all looked at it and Aira sat close to her Dad.'

'Toby returned home about 40 minutes after Mahi and Aira. He had been at the pictures and had had to be fetched out from the picture house. Toby was more contained. When he went in he went straight to his mother and wept quietly. There was no sound but there were drops on his glasses and he wiped them away. He wasn't embarrassed.'

'The family sat close together beside Ani expressing many thoughts and feelings. Mahi talked again about Ani's dream which she felt had some significance. She thought that several significant things had happened that morning. Ani had appreciated the visit from the nurses and the care that they gave him that day. He had especially appreciated the visit from one of the nurses who had looked after him while he was in the hospice. He had thoroughly enjoyed the massage that the physiotherapist had given him that morning and had found it very soothing and relaxing. The physiotherapist had taught the children how to massage Ani's feet and she had given a massage also to Mahi who said that it

felt marvellous. There they sat, close to Ani, able to let go and speak of things that were meaningful in spite of the suddenness of his death.'

'Peace descended on the family. Ani was in his own house, where he wanted to be. He had wished to stay at home despite all the difficulties. Home meant everything to him and he had just lived for the children. So there he was, in his own little lounge with everything in it, the couch, all the chairs, the big lazy-boy right in the centre taking up most of the room, in front of the fire where he had been able to see the television which he so enjoyed, the doll's house and the box of toys. It was so crowded you could hardly get in the door. But it was home and a place of love and the way the family coped was an expression of that love.'

'When I had visited on the Friday afternoon I noticed that Aira had a little seal in her hand. Her father had made it at his work place from molten vinyl and had turned it into a lovely smooth shape with two appealing eyes, and it snuggled neatly into her hand. Aira was very proud of the fact that her father had made it for her – it was a lovely thing to keep, something he had made. During the afternoon Aira asked for the seal and a frantic search took place until it was found. Aira took the seal and held it and then placed it on Ani's shoulder and rested it there. It was only after this that she was able to leave her mother's side and sit down on her own on the other side of her father. She continued

to stroke his arm, looking up at him. She sat there on the edge of the couch and just looked. The seal was on his shoulder and she looked at him and looked at the seal and stroked his arm. Aira had cried a great deal and finally exhausted she got into her sleeping bag on the couch and went to sleep beside her father.'

'Late in the afternoon, Mahi said it would be nice to put on an Elvis Presley record. They had enjoyed Elvis together and this is what Ani would have liked. Mahi sat there and sang a few lines from time to time. She sat there close to Aira asleep on the couch, Toby there too.'

Ani was embalmed and his body was returned to the home. On Sunday night they slept as they had always done, Ani lying in the lazy-boy, Mahi sleeping on the couch and the two children in their sleeping bags on the floor beside them.

A nurse went in on the Monday. 'Ani was still there, looking peaceful, all done up in a suit and tie. Aira said he didn't ever really wear a tie, but she thought that he looked lovely.'

It had all been very peaceful and very affecting. Ani had remained and died in his own surroundings, in his own home with his family and young children. In death, Ani continued to be a living part of the family, and so he will endure. The family were able to express themselves and had found peace. For Mahi what was important was that she had done what she set out to do, to look after Ani at home as he had wanted.