

The integration of living and dying (2)

Case histories

In 2005 I told the staff of the Hospice Foundation of Taiwan that I had no more ideas to share. I suggested that they invite a new speaker next year. They responded, “You may have run out of ideas for the present, but during the next year you will have new experiences and learn new ideas that you can share with us”. They were correct. Since I visited in September 2005 I have had several profound experiences, mostly learning from my patients. I wish to tell the stories of three of them.

Kevin is a 41 year old man who had a very traumatic childhood. As a small child he was fostered, but did not feel really loved by his foster-parents. As a teenager he left home, became a drug addict and was imprisoned. In 1986 at age 21 he was released from jail. Acting on impulse he climbed down the outside of a multistorey carpark, pretending to be “Spiderman”. A few days later, intoxicated with alcohol, he tried to repeat the descent, but slipped and fell to the ground. He landed on a metal roof, which broke his fall. He sustained a fractured spine at T11 and became paraplegic. He lived with a friend for many years, developing severe pressure sores on his buttocks. Eventually he had a left hindquarter amputation. He continued to develop pressure sores, with massive infections of the buttocks, eventually producing rectal and vesical fistulae. In March 2006, aged 41, emaciated, anaemic, and infected, he was transferred to the Murdoch Community Hospice to die.

Maree is a 38 year old school administrator, married to a school principal. They have three children aged 17, 15 and 11. In December 2003 Maree had strange cramps in her left leg. A neurologist told her the problem was emotional and arranged counselling. Over the next year she developed weakness in the left leg, and also the left arm. In January 2005 a second neurologist told her she had motor neurone disease.

Maree was admitted to the Murdoch Community Hospice for two weeks in April 2006 to allow her family to have a rest. She was admitted again in July 2006, so that her family could have a rest during the school holidays. She could no longer feed herself, and spent her day either in bed or in her new electric wheelchair. She is holding a big party on August 12, with 150 guests. This will be a celebration of her life, a chance to thank all her friends for their love, but also a recognition that she will die soon.

Jack was a prominent businessman whose manufacturing company employed more than 500 staff. He was born in 1913, the eldest of 7 children. He was forced to leave school in 1928 at the age of 15 to earn money to help feed his brothers and sisters. He retired at the age of 80, but continued to be very active. In 2001 he and his wife shifted into a new retirement village. His wife's health deteriorated and he became her main carer. In 2003 she became so frail that she shifted into a nursing home. Every day Jack drove his car 5km to the Nursing Home to sit with her and read to her. In April he developed acute heart failure and renal failure, and spent a week in hospital. The doctors told him that he would die within a few days. His 3 children and their spouses offered to take him home to care for him until he died, and Jack willingly accepted their offer. A hospital bed and an oxygen concentrator were hired, and assistance was arranged from the Silver Chain Hospice Care Service, who visited every day. Most nights a Care Assistant stayed at night so that the family members could have some sleep. Jack was able to plan his funeral, give instructions to his family, and say goodbye to his large family: ten grandchildren and five great-grandchildren. He died on the seventh night, aged 92. His grandchildren and great-grandchildren decorated his coffin with drawings, palmprints and messages. At the funeral ceremony they released dozens of balloons. After the funeral service there was a large service of celebration and thanksgiving for his life.