

In memory of Rosie

In October 2002, I first went to Rosie's home for four hours each week. She had been diagnosed with motor neurone disease, a degenerative condition i knew very little about. There i was, prepared to be unconditionally present and loving.

Rosie could still walk at that time, with the aid of a walking frame. She had lost her power of speech and the ability to chew food, but not her capacity to command. As her control over her body steadily deteriorated, the need to control her environment and those in it increased. If you left a cup on the coffee table or there was a cushion out of line on the sofa her finger would continue pointing until order was restored.

Yet looking after Rosie was unpredictable. There are no certainties about how the disease progresses, which connections to which muscles will fail or at what speed. Every day was a lesson in being present for however things were. As the months went on, Rosie fell more often until she couldn't walk anymore. Her tiny, 67-year-old frame was a mass of bruises and I had to learn how to transfer her from armchair to wheelchair to commode to bed as gently as possible. And how to do very basic physical things for her without causing her a loss of dignity.

Rosie's dying taught me about the limits of my own selfishness – that it's hard to meet your own basic needs when someone else's needs demand every ounce of your energy; and how to give what she needed and not what I thought she should need. Her needs were so great that at family meetings there would be at least 12 people around the table, all representing various care agencies and hospices. In the year I spent with Rosie three home care organisations gave up being able to offer support, two nursing homes were severely taken to task for neglect and abuse during her respite care weeks, all her friends (with one exception) stopped visiting. We were all being tested to the limit and found inadequate at times.

Rosie's will to live was phenomenal. Most of the time she was convinced she would walk and talk again. It was a strange kind of denial, punctuated by periods when her response to talk of death was to throw her arms open wide in a gesture of unmistakable and unconditional love and acceptance.

In the last two weeks of her life my patience with her increasing need to control wore as thin as her skeletal frame. Whatever i did, she wanted the opposite. Both of us welled up with sheer bloody frustration, not wanting to be in the situation we found ourselves. And then i realized that, no matter how hard caring for Rosie became, I would not walk out on her because she could not walk away from her own dying. It was part of our shared human condition and to think that i could wander away to more pleasant activities was a convenient illusion. I chose to accept.

I thought i was prepared for her death but found, when the time came, that I was not. She had just been given a diagnosis of three months to live. I had a fixed idea that she would die in her bed one night through being unable to breathe and had assumed there would be no time to say goodbye. Life delivered another lesson – that death is certain but when and how it happens is always uncertain. Apparently, Rosie spent her final 24 hours visibly fighting for her last breath. I

had failed to plan for uncertainty, had not made my wish known to be present with her as she died.

When the news came i took my meditation cushion with me the next day to the funeral home and sat with Rosie one last time. Her body was resplendent in pink lace and pearls, her face unlined in a way i had never known it. The pain was gone, and so had Rosie. I lit a stick of incense and, on an empty Tuesday afternoon, sat in voiceless silence with the consciousness of a human being who had taught me much.