

A Caregiver's Journal on Coping with Death

In the 1980s, my mother-in-law was sent to a nursing home as we were unable to continue caring for her adequately. During her final days in the hospital, it broke our hearts to see her plugged to various tubes. I still remember that early morning when the hospital called us. Upon arrival, a sense of joy and relief washed over me seeing that she was sleeping peacefully on the bed, with all the tubes removed.

Not knowing that she had passed on, I ignored how the other patients tried to inform us of her passing through hand gestures, while under my breath blaming them for such behavior. We called on the nurses to enquire her state of condition but all they did was to return to her bedside, closed up the curtains, and the next thing we saw was a table-like cabinet being wheeled in and shortly after being wheeled out. It was shocking for us to see the empty bed.



In 2002, my father-in-law was diagnosed with terminal stage of prostate cancer. This time, I was more experienced and wise, so I consulted his children on the modus operandi that I should follow if their father's condition worsen while at home.

Viable, feasible and practical options for us then were:

- (a) Send him back to hospital despite knowing that nothing much could be done,
- (b) Notify them to be present as he breathes his last breath,
- (c) Identify another family member who would help to contact and inform the rest of the family while I concentrate on attending to his needs.

My father-in-law, being a traditional Chinese man, wanted to leave some gifts for his descendants. Thus, I went hunting around, often without success, and eventually purchased enough gifts for all his children and grandchildren. While I was attending to his specific instructions to check that everyone in the family has a gift, our domestic helper knocked on my door to announce that "gong gong" looked strange and was not responding.



I contacted the designated family member and a team of hospice staff visited to ascertain the situation and subsequently, issue the death certificate.

As for the case of my mother, she unfortunately had to wait for me to return from the United States while I settled my son into university. The moment I returned, I was ferried to the hospital, not realising that that will be my last time seeing her. Although her feet were swollen then, she looked calm on the hospital bed.

"Mummy, I'm back to see you. Why don't you open your eyes to look at me?" I said.

A few tears rolled down her left eye, so I knew she heard me.

Later on, news that our mother had passed on came as I was talking to my sister on the phone about her condition for the past few days. I remembered that my mind went blank, I then let out a scream uncontrollably, shocking the whole household.

Even though I had experienced deaths of my dear ones, it was the death of my mother that hit me the hardest, and the healing process continues. I tried to contain my emotions, and bury the loss in my heart. I did not know then that I should open my heart and speak about my feelings. I did not know who to approach for help, or how to grieve – other than crying hopelessly.

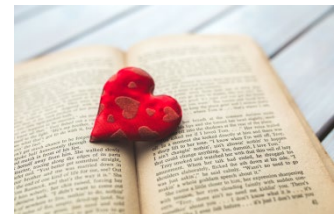
Later in life, my involvement in voluntary work, the training and guidance by the counsellors at Tsao Foundation, together with my faith in Buddhism, slowly opened up my heart. While my emotions still run havoc when I hear of deaths, I have become more accepting that birth, ageing, sickness and death are the different stages of every person's life, and would softly wish them well and happy, and share the merits that I have accrued.

I believe there are three parts to the caregiving process:

- 1) Before caregiving commences;
- 2) During the caregiving process – there are now many information on this aspect;
- 3) After caregiving duty ceases – caregiver continues to require support during this process.

Other than the termination of external assistance to take care of the patient, the caregiver's emotional, social, psychological and other needs have to be looked into. One common situation is when the caregiver suddenly has all the time in the world but has no one to care for or turn to. Often, caregivers were also guilty about not caring well enough.

With acceptance of the normal life cycle, appreciation that we have tried our best and have done well enough, and that the deceased will always remain as a part of my life in each and every moment even without their physical presence, my sense of peace and joy slowly returned.



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