

THE CHALLENGES FACED: BECOMING AN AMICUS | DEATH DOULA | END OF LIFE CONSULTANT | MIDWIFE FOR THE DYING

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To put it in a nutshell, my desire to work with the dying is the culmination of interest, experience, knowledge, wisdom, education, skills, personal values, plus spiritual and philosophical leanings. It is a cultivated intent to ease the pathway for the dying person and their loved ones. To advocate, to provide a presence, to bear witness and to mediate. Of primary importance is to 'hold the space' with calm abiding equanimity whilst having the wherewithal to resolve any issues that may arise and disseminate information with compassion and empathy. Our birth presents us with no choice. Approaching death, if we are fortunate enough, we do have choices as to how we would like to die and what we foresee will occur once we are dead. To honour the choices and wishes of the dying person is one of the greatest gifts one can bestow upon another human being.

As a young child around the age of five, I was 'inadvertently' introduced to the mysterious concept of death. Unbeknownst to the adults around me, I often overheard their various and detailed conversations about: 'Uncle Stan dying (very quickly) of leukaemia' or 'the man who dropped to the ground in Nelson Street and despite a passing stranger pummelling his chest until his ribs broke, he couldn't be revived'. But, did I actually witness this and being too young to comprehend, repress it? I can assume that this is the case as I do have a visual memory of the event....Subsequently, there is a vivid recollection at age seven, when witnessing the death of our family friend and neighbour Claude Breydon. He happened to be the Mayor of St.Kilda at the time and having collapsed in his lounge room, his wife Marjorie flew into a panic, despatching their daughter and my friend - 8yo Joy - to our back door banging and screaming for my Mum and Dad to come quickly. In an instant, my parents disappeared down the back laneway behind our shop leaving me alone and with no other option but to proceed with great trepidation in the footsteps of my parents. Once at the scene

of the casualty, I stood unnoticed peeking around the door, and saw Claude lying on the floor, blue/grey and unconscious, propped up on pillows with my father frantically working to save him – all to no avail. Claude was dead via cerebral haemorrhage at 55. What this scene transmitted to my young psyche was the sheer panic, the urgency, the despair and the suddenness. The absoluteness of death.

And therein lay the foundation for my childhood terror of death – a neurosis that¹

rendered me with great separation anxiety – that left me staring out my bedroom balcony window – above the corner of a busy intersection – hyper vigilant to ambulances and police sirens – watching and waiting for my parents to come home from their occasional forays out at night. I was that anxious, I can remember imagining my parents’ death notices in the paper. With hindsight, it was irresponsible and tantamount to negligence for my parents and all the adults present in my formative years to talk unguardedly about matters in which a solitary and peripheral five year old was too young to emotionally and psychologically process.

In those days - the 50’s and 60’s - talking about illness, death and other people’s tragedies was a prerequisite for many adult conversations. Reading the death notices in the newspapers was a daily must: ‘Did you hear who died yesterday?’ ‘Did you hear what happened to poor Mrs. Bevan?’ ‘They had to remove half her intestines’. Perhaps this was all part of a post WW2 cultural milieu – perhaps socialised into families as a relic from WW1 and the resultant deaths of millions from the Spanish flu. And despite the popular topics of illness and death, I never witnessed any rituals, never heard of any memorials or services and death and dying was always couched as the worst experience anyone could ever encounter. The person was there, and then they were gone – with a fair amount of angst and negativity in between. Understandably, death to me came to mean drama and trauma. Death meant confusion, fear and loss. It meant emotional turmoil and the terror of non-existence. And there was nobody to notice, comfort or explain. No spiritual guidance, no empathy and no respite from the external anxiety inducing mechanisms or the carelessness of adults. So,

I was compelled to discover for myself; I had to self soothe and forge my own path toward an understanding and acceptance of death. It is an ongoing journey of discovery.

Fast forward fifty years or so, I now do death well. I have done death well – a few times now. I can be with the dying when those around me are stricken by fear, when family members are unable to get over their own emotional turmoil, their prejudices and their unhealed, unresolved conflicts with the person dying. I can be present and hold the space. I can be the calm amidst the storm. I have an acceptance, an equanimity, compassion, empathy and a commitment to ensure that the journey of the dying person is in accordance with their wishes. To that end, I will advocate for them in any way I can. I will endeavour to assist in the smoothest and most healing transition possible. One may well ask, ‘how did I get from gross fear of death to wanting to assist the dying?’

At some point, I became aware that I had to choose whether to continue suffering in fear for the rest of my life or, change my cognitive processes and habituated reactions to that fear - that I could choose to improve my emotional intelligence, become responsive rather than reactive and discipline my mind. Therefore I have spent many years cultivating a Buddhist inspired way of being, developing meditation and mindfulness skills to discipline my mind and to maintain equanimity in the face of what life presents and also in the face of death. It has been a process of spiritual, philosophical and psychological evolution alongside the gathering of knowledge and wisdom. Studies in Buddhist psychotherapy, spiritual care, chaplaincy and previous education as a death doula have honed and channelled my skills.

Attending to and supporting the dying process with both my parents, with relatives, friends, horses, dogs, other pets and in March 2017, with my beloved partner, Peter, has made me realise how much of a privilege it is to bear witness to the dying person and their process. There is much beauty, grace and humility. It is a profound and humbling experience and deserves the greatest reverence. My parents were aged. Dad was 82 with slowly progressing kidney cancer and Mum was 93 having had Alzheimer's disease for 17 years.

However, Peter was a trial by fire. Belatedly diagnosed with oesophageal cancer, he died within 8 weeks. What enormous learning experiences! Oh, the intensity of 8 weeks and the incredible amount of learning, advocacy and heartache! What a challenge! Medical, emotional, physical, spiritual, situational, financial and one of the biggest challenges – dealing with the aftermath – Peter dying intestate (despite) many pleas to make it otherwise – and attempting to mediate with his three semi estranged and troublesome USA children. The challenges that one must face as an amicus, death doula or, midwife to the dying are many and varied. One must both hold the space and act as an intermediary. Issues arising may take the form of family disagreements, unresolved conflicts, estrangements, financial contingencies and cross communicating between family, patient and medical/allied health care teams. Even the differing opinions of doctors and the constant and often non-communicated changes to medication and treatment present obstacles. Then there are the families and patients who want to cling to life, to deny the reality of the situation, to avoid the truth of the matter. The amicus must act with discretion at any given moment, must be both a calming presence and a resolute advocate.

And one of the greatest challenges and one commitment I am personally dedicated to, is honouring the dying persons' wishes and their right to die in the way they see fit - to ensure that their instructions pre and post death are diligently followed₃

– despite any reluctance to or, desire to the contrary emanating from loved ones or family. Often, this requires great diplomacy and conflict management skills. To that end, I would see my role as an amicus or midwife to the dying as both immensely rewarding and constantly challenging - requiring both a calm abiding presence and a combination of essential skills. It is certainly of unquantifiable value, a wonderful privilege and one of the greatest agents through which to best serve a fellow sentient being. Am I scared of dying? Intellectually, no. Emotionally, maybe just a tad!