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Death as a threshold: being with a person as they are dying

Abstract:

In *The Art of Living and Dying*, Osho writes that the West attempts to hide death. This is in spite of the increase in representations of death and dying in non-fiction and fiction writing, film and television entertainment, documentaries, news, sociology and psychology this century. There is however, limited writing about everyday, personal experiences of dying and death, perhaps because we find the personal too close to disclose, or language and grammar inadequate. This paper discusses aspects of what it means to be with, or alongside, someone who is dying from a personal perspective. It follows Kübler-Ross in suggesting that we need to speak and listen meaningfully about experiences of those who are dying and those with, or alongside, them. It draws on the experience of being with a friend and an uncle in the final weeks of their lives to suggest that society would benefit from confronting death productively, accepting that we all die and engaging positively in the process of dying with the person who is dying, those alongside them, family, friends and community. Writing and talking about death, requires taking account of bodies – those of the person who is dying, as well as those who are alongside them.

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In the final contented hours of a friend's life, she said that she was ready to die. On the final day of my uncle's life, I asked him if there was anything he wanted, to which he replied, 'this is new for me so I do not know what I could need'. Where we might usually associate dying with loss and fear, my uncle identified dying as a new experience in his near future. Many Australians have limited opportunities to speak about and listen to – or read meaningfully about – personal experiences of death and dying including that of close family and friends. A friend whose baby died many years ago now, of a genetic condition, lives with the loss of her child and of not talking about him because others did not know how and did not want to upset her. More recently, a friend whose husband died of cancer said a number of times, 'we don't learn how to talk about death'. In the below, I draw on personal experiences of being with a friend and uncle as they were dying and my responses to being alongside them to discuss the affective responses of those who are with or alongside a person in the final stages of their life.

In *The Art of Living and Dying*, Osho accuses the West of making death taboo and thus hiding from it (2013: 6). This is in spite of the increase in representations of death and dying in non-fiction and fiction writing, television news and films this century in the West. These representations, however prolific, are 'death at a distance'. They do not necessarily provoke us to confront death personally. Personal experiences of the death of family, friends and others incite physical and emotional reactions and make us think about dying and death. Death elicits a myriad of responses including acceptance, denial, relief, grief, anger and resignation. These depend on relationships, whether the person had lived a fulfilled life, opportunities to speak for a final time or not, as well as the age of the person who has died and those remaining.

Despite the taboo Osho identifies, in Australia there is an increasing focus on quality of life and dying influenced by the 'baby boomers' (Swerissen and Duckett 2013). The medical and legal professions are urging people to plan for death including: whether, and under what conditions, they want medical treatment to prolong life; the type of funeral they want and involving loved ones in decisions. Creative writing including Donald and Myfanwy Horne's *Dying: A Memoir* (2007) and Kate Grenville's *One Life: My Mother's Story* (2015) prompt us to confront dying and in doing so celebrate life. Donald and Myfanwy Horne do this by providing an account of the last months of Donald's life and the couple's coming to terms with the loss of their relationship, which concerned them more than his dying. Grenville's account of her mother's life is a tribute to a woman born in 1912 who worked, studied, started her own business, had relationships and children. These writers share their thoughts and feelings about life, death and loss in ways that connect to many peoples' experiences. Their openness to expressing loss, fear, acceptance and gratitude allow others to connect with them and prompt useful conversations. For instance, Donald and Myfanwy Horne accept Donald's approaching death, and grieve the impending loss of their relationship rather than death. Their writing is significant because it voices the concerns many people have but do not speak and therefore do not benefit from the experiences of others.

Rothschild (2000), Massumi (2002), Gregg and Seigworth (2010) and Ahmad (2010) examine affect, the instinctual, non-conscious, cellular autonomic impulses prior to emotion, to understand the connections between the physical body, affect and emotion. This growing body of research is productive for understanding personal responses to dying and being with someone in this process. It is also helpful for writing about these experiences because it provides a language for expressing impulses that are often not spoken. For example, Massumi's explanation of the body's readiness to respond to 'being right where you are intensely' (2002: 35) is useful for describing what being-towards-death authentically means and expressing being-alongside others as they experience dying and death. The intensity and complexity – love, sympathy, tiredness, inadequacy and awe – of this experience is difficult to express. Part of the complexity is because: 'affect is always entirely *embodied* [emphasis in original], and [yet] it is never entirely personal – it's never all contained in our emotions and conscious thoughts … it's not just about us, in isolation. In affect, we are never alone' (Zournazi 2002: 214).

When alongside my friend and uncle, the connection between our bodies, nurses, the bed, the smell of hospital cleanliness, the smell of bodies and change was a contagion of affect anchored in that place, at that moment. It is not possible to isolate bodies, smells or feelings and neither was it possible to control them; they operated beyond everyday ways of being.

To put into words, spoken and written, the experience of being alongside a person during their dying, requires finding language for describing what is happening to the self as part of that process. We do not commonly do this. During such a time, the focus is predominantly on the dying person. This can mean that those alongside might push themselves to be happy, to talk, to remain with the person when tired or concerned for other demands. It may be confronting to witness care procedures. This is complicated because the one who is dying is usually an important part of those other peoples' lives. At any moment, a person might feel inadequate, tired, emotional, joyful and more. Rothschild in *The Body Remembers* provides readers with the valuable reminder that bodies are visceral. Hearts pump blood, rapidly in response to stress, and body temperature fluctuates as an effect of joy, love, shame and fear (2000: 42). The person alongside the dying person may be in a heightened state so that their body's autonomic and somatic physical reactions and emotional responses are stretched. It is similar to stressful or extra busy times at work when a person keeps going, knowing the situation will change. When it does, the person's body might respond with a cold or a migraine. This is a cue to take time off, relax and care for the self. Writing and talking about death requires taking account of bodies – those of the person who is dying as well as those who are alongside them.

Writing about death and dying and drawing on lived experiences to do so requires reflection, documenting and interpreting past personal situations. The research methods used by ethnographers – in which the researcher observes, interprets and describes an event or experience (Aunger 2004: 152) – and autoethnographers, employing an analytic approach in which the researcher interprets her world (Pace 2012: 3) when the researcher is involved in the experience (Terszak 2008), are useful for doing this, albeit that the writer uses them to guide their reflection and writing rather than to collect data. In autoethnography, the researcher's values, beliefs, expectations, and personal relationships influence the research (Partington 2002: 149) and the researcher is thus a narrator. Reflecting on and writing about personal experiences of death involves the writer treating their lived experiences as data and describing, analysing and interpreting the experiences, as much as possible, as an observer with the understanding that their 'personal relationships' will influence what is written substantially. In this way, the writer contextualises experience within a broader cultural context to facilitate social understanding, in this instance, of being alongside someone who is dying (Pace 2012).

Therefore, when I reflect on being with a friend and uncle when they are dying, I extrapolate these experiences to articulate more broadly, what it means to be with or alongside a person in the unique and intimate experience of dying. By doing this, I am able to highlight the complexities of acknowledging and talking about affect in this situation where the rules about what can be said are in flux, allowing for conversations that might not otherwise occur. Similarly, spontaneous, non-negotiated physical intimacies such as touching occur. Historically, in Irish and other vigils and wakes, there was a cultural legacy of dying and being with others in this process, which included talking and touching. Friends and family shared accounts of practical experiences, thereby teaching how to be with those who are dying. With cultural changes including migrations, these practices largely ceased and communities lost valuable knowledge about dying, death and grief. This may go some way to explain our contemporary reticence to speak about death and dying and our loss of opportunity to articulate our personal reactions within the process.

Being with someone means to share as fully as possible in what you are doing together; in this case experiencing the final part of a person's life with them. It is not being the same, doing the same thing or experiencing the same event. Rather it is being as present as possible in the same event such that you are connected in spaces, smells, sounds, physical and emotional interactions. Affect is contagious jumping from one body to another, holding, connecting and repelling. As Anna Gibbs writes:

> Bodies can catch feelings as easily as catch fire: affect leaps from one body to another, evoking tenderness, inciting shame, igniting rage, exciting fear – in short, communicable affect can inflame nerves and muscles in a conflagration of every conceivable kind of passion (qtd. in Ahmed 2010: 36).

How a person in pain, frightened about what is happening, wanting to die but holding on for others, expresses themselves to medical staff who they may have no strong personal connection to and to a loved one might be different. A person might be able to tell a nurse that they just want to die but not be able to do so to a husband or child. He or she might maintain professional distance with a nurse and not cry because they are anxious about what is to come or what they are leaving behind. Therefore, being with someone who is dying involves spoken and unspoken promises of care. It requires an acceptance of responsibility for being with them, doing and saying what is required to support and share with the dying person. It includes accepting the privilege, joys, uncertainties, pain, and feelings of selfishness, inadequacy and more.

Being with someone who is dying is challenging. It may push us in ways we do not expect and ways we do not want or know how to own. This is an important and under explored experience that can leave us with negative thoughts about our self and feed feelings of inadequacy. Being with someone, in the fullness of the sense I mean here however, is not one-sided. The person who is dying does not receive a disproportionate benefit. This is a difficult point to articulate.

Georgina (pseudonym) was a significant person in my life, though not someone I spent time with consistently. When I visited her some weeks before her death, she was anxious, perhaps frightened. She was not afraid of dying but rather of not having intimate physical and emotional connections throughout the process. Georgina has three loving sons, two who visited and one who was able to be with her regularly. However, they touched her as sons conventionally do. Georgina needed more as I learnt from her response to my lying on the bed with her, our bodies touching and warmth spreading between us. I assured her that she would not be alone. She relaxed into the final stage of her life. We were both reassured. This made moving to a hospice for the final weeks of her life – which was her desire – a positive process in which she could readily access medications and nursing care within a private space and with family and friends present when they and she wanted.

During the following few weeks Georgina reminisced about her childhood her parents, sister and grandmother. She talked of two husbands and their deaths. Georgina spoke too of relationships and family issues she felt she had dealt with badly but within her limits. By touching, talking, laughing she relived parts of her life so that past and present were continuous. The doctor and nurses took care to speak to us about pain, comfort and medications. Increasingly, I assisted her in the toilet and shower. As the painful periods extended, Georgina resisted getting out of bed and was ready to die. Finally, as we waited for nurses to administer morphine, which, because of her weak physical condition, would cause her to lose consciousness, we sat and talked. I brushed her hair, as I had during the past days. She leaned back on the pillow. Wanting to distract Georgina and myself from the pain, I told her I would pass on her final advice to her sons. This amused us; her sons were not open to 'interference'. I offered to tell her eldest to allow his daughter to move in with her boyfriend and the next to leave the political party of which he was a member and that she opposed. Georgina laughed. The nurses came, read her name bands, checked the injection details and asked if we were ready. Georgina nodded. I whispered yes. I thanked Georgina and told her I loved her. One nurse put the needle into Georgina's arm. It hurt, she gasped, I made a joke about her and her relationship to her youngest son. Georgina laughed again; 'that is just what you would say'. Our play with 'Georgina's advice' to each son concentrated her past in the 'living present' (Williams 2011: 33). We looked at each other. She sank into the pillow and closed her eyes. I sat and held her hand.

My uncle was a man with a photographic memory and an eye for detail. He came to live with my husband and myself in Western Australia. By this time, he rarely left his small flat at the back of the house. However, he watched history, geography, science, and films about train journeys particularly across Europe, the United States and Australia where he had travelled by train. In these ways and by recounting these journeys, he was continuously 'bringing [his] past up to date in the present, through memory' (Zournazi 2002: 215) and enjoying the experiences again.

A week before his death we moved to a local hospice where he could have morphine for the pain caused by his kidneys ceasing to function. It was comforting to me too. Being alongside my uncle invoked many complex responses. Childhood experiences of trips to Perth on the train, a pie in the Post Office or train station cafeterias, his finding a coin and being as pleased as a child might be with treasure, mingled with memories of his long absences at times of parental neglect. In his older age, my uncle had learnt to ask others how they were and to articulate his feelings. This did not come naturally to him. He was relatively isolated due to limited social skills, regarded life as a biological/social process largely explainable through science, a subject of which all aspects interested him. The final few years of his life were often painful because of a misdiagnosis of Parkinson's disease.

He had no religious beliefs and no distress about thinking of himself beyond the moment of death. He accepted that, as matter, the body disintegrates and, as energy, the 'incorporeal dimension of the body' disperses. While it is not always possible, Elisabeth Kübler-Ross' advice to "[l]isten to the dying [as] they will tell [us] everything [we] need to know about when they are dying" (1970: xv) is useful in guiding us in how to be with a person in this process. However, the dying person may not know what they want and if they have avoided talking about dying or have not had the opportunity to do so, they might not be able to. When I asked my uncle if he wanted or needed anything from home his reply was, "I haven't done this before so I do not know what I might need". Because of his attitude to life and the body he was speaking about moving through the thresholds between life and death while being 'only in the present in passing' (Zournazi 2002: 212) and looking to an unknowable future in anticipation of the experience. He spoke as if he was inquiring into a new topic of interest. In Heidegger's terms, he was engaging authentically with the process of dying, accepting its inevitability in a 'freedom towards death' (1985: 311) that was contagious. However, other people in this situation may not be able to ask for what they want because dying is not something about which they talk.

I never knew anyone's death to particularly upset my uncle, though he was concerned about how people died. Likewise, he accepted that the incremental process from last breath to himself as no longer human was unknowable and he wanted to 'be present' in the experience. I revisited my uncle's dying when, a week before her death, Australian art historian Betty Churcher spoke about anticipating death as an experience and wanting to be as conscious as possible of the event (Sales 2015). It is not that either of these people wanted to die, rather that they accepted death as an inevitable component of life and were open to both the process of dying and speaking about it as much as possible.

When my uncle was in severe pain, he accepted some, though not large doses, of morphine. At a point when I was tired and he was in pain I told him, I did not know how long I could cope with the process. I am unclear whether I was referring to my ability to sit with him, stay awake, spare the time, see him in pain, listen to his at times terse interactions with nurses, or confront decisions I had taken about his life in the previous months – some of which had caused him physical and mental harm and discomfort. I was self accusing. I knew that his annoyance with nurses was about maintaining control of his body and whether to eat and drink or not. This was partly a response to previous months and doctors not listening to him about medication that he – correctly as a doctor later verified – said was incorrectly prescribed. It caused him pain and eventually kidney failure. I did not intervene on his behalf. I felt ashamed for not supporting him. This still worries me. It is not something I anticipated feeling or having to resolve later. I have not heard anyone express similar feelings and discussion of such feelings are not part of the current limited discourse about death.

Some hours after my uncle's death, a nurse asked if I wanted to help her bathe and dress him as part of saying goodbye. We stood on either side of the bed across his naked body. The nurse asked who he was, what was our relationship and how I was. She began to wash. I mirrored her washing. We washed ears and neck, lifted his legs to wash the back of his calves and thighs and raised his torso to wash his back. This washing was not perfunctory. It was an act of respect for this man, for my relationship to him and for the palliative care nurse. It was an active engagement with his dead body. Later, as I reflected on this it helped me with my shame but could not resolve it. I felt that I had not been with or alongside my uncle as I should have been in the months before his death.

Both Georgina, by recalling her parents and childhood, marriages and children, and my uncle, through speculations about the changes he was undergoing, lived intensely throughout their dying. They bought past and – in my uncle's case future oriented – experiences together in the living present, which we knew were the final moments of their lives. Importantly, they were able to just be. Their deaths would have been significantly different if we had focused on loss. If I had focused on Georgina's and my uncle's dying in terms of my own loss, they may, for instance, have felt a need to look after me, to take care of my feelings.

The role people continue to play in our lives after their deaths depends on our relationships to them, the way they died and our ability to be with them or, if we are not directly involved, to be accepting of their death. The person remains in the lives of family and friends by becoming 'the standard for perfect scones', 'the measure of ethical behaviour' or 'the reminder of how to laugh at our selves' (Williams 2011: 126). They are part of us and continue to influence how we relate to the world and others. We look at photographs, recall and retell stories, we think ourselves with them, seeking and taking the advice, they might give if here in body. This cannot be commensurate with having the living person, which is not possible. Rather, as Deleuze writes, they 'pass away and return for us as … difference' (1994: 121); they are part of the refrain (42), which we sing repeatedly and, as such, the person remains with us.

Our relationships to those who have died and the effects change over time. 'The dead continue to surprise [us] with their presence' (Howarth 2007: 213). Georgina is with me as I pick a rose from a bush she gave me or use her teapot; a childhood memory of caring evokes my uncle; as does looking in a mirror and reflecting that noses grow forever and mine is already nearly as long as his was. They travel with me, appearing at other family members' houses, they resist being pinned down to 'past relationships, fading photographs or lost memories' (Howarth 2007: 213). Because as Popova reminds us, 'Memories are not fixed or frozen, like Proust's jars of preserves in a larder, but are transformed, disassembled, reassembled, and recategorized with every act of recollection' (2013).

Being with Georgina and my uncle as they were dying was a humbling experience. I was able to provide Georgina – who was ready to die but also anxious – with comfort and security. This included having physical contact; knowing there was someone who cared about her wellbeing and would speak up for her in ways she wanted; having someone with whom she could talk about the unknown in real, non-euphemistic ways. My desire to be with Georgina – to assist with showers and eating, and listening – was part of my response to her care for me as a teenager. It was not a sense of obligation, or of being sorry because she was dying, rather it was a contagious affect ignited in the moment of lying together and talking about the practicalities of dying.

There is much to be gained by opening up discussion about the positive and negative experiences of being with a person in their dying, and with others sharing such experiences, because then we enter into dialogues. These may take many forms including writing from experience. Analytic autoethnography is a useful method for researchers who are drawing on personal stories, including those drawn on in this paper, to address social concerns such as limited discussion of dying and being alongside someone in the process of dying. Affect theory is useful for articulating embodied emotional responses to dying and death.

Heidegger (1985), Deleuze (1994), Massumi (2002), and Osho (2013) remind us death is coextensive with life and we move towards death from the moment of birth. It is strange then that we can find death and dying confronting, do not talk about it enough, including with the dying person. I had to feel my way around, sometimes reaching the right spot but at other times stumbling and not providing what was wanted. Whilst we shared the process, the experience of dying was Georgina's and my uncle's. It was unique to them. It was the only chance they had to experience dying as fully as possible, in and of itself. While Kübler-Ross' advice about listening to the dying is valuable, it does not explain, or help us understand our experience of being with someone who is dying, which is in turn unique to us. It is therefore important to share these experiences through speaking and listening with others and, of course, writing about them.

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