

## A Good Death?

Andrew Cooper

'It frightens me the awful truth of how sweet life can be' Bob Dylan

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### **Abstract**

*This short paper offers a set of personal reflections on the contemporary idea of 'a good death' which has been a theme in the writing of philosophers since classical times. The hospice and palliative care movement has made immense progress in creating social and psychological conditions in which we can 'die better'. But such experiences of dying are still the exception rather than the rule, and for many dying and death remain terrifyingly painful and unpredictable. The psychological challenge for us all is how to relate to the dying as they are dying, and how as we die we relate to the living. I reflect on my own experience of my father's death, and a moment of fleeting, painful but genuine contact between us about his process of dying, and describe how my view of this altered in the course of writing this paper. Atul Gawande's idea of the 'hard conversations' we must learn to have as we, or our loved ones approach death, are enlightening. But ultimately I argue, we die alone, and how we are, or are not, 'held in mind' as we approach death may be an index of the nearest we can approach to the idea of an 'afterlife' – a confidence that we will be held in the minds of others and remembered long after we have died.*

### **A great place to die?**

"I wish I could tell people how nice it can be to die of cancer". This is the first line of Colin Murray Parkes' foreword to Elisabeth Kubler Ross's classic (1969) text *On Death and Dying*. He is quoting a woman who died peacefully in a Hospice a few days later. "Can be" – but, too often, is not', Murray Parkes adds a few lines later.

The UK is now officially the best country in the world in which to die, according to the 2015 Quality of Death Index (EIU, 2015) which ranks palliative care across the globe. Indeed with a score of 93.9 out of 100, it can't get that much better. Iraq with a

score of 12.5 props up the list of 80 countries surveyed. I am sure the irony of this will not be lost on readers, though it is not a point on which I want to dwell. The UK picture probably ought to provide us with some reassurance, as we contemplate more directly our own relationship to dying, which is part of what I want to help us do in this paper. But I wonder how much comfort it really does offer?

The hospice and palliative care movement in this country, and globally, have positively transformed our social capacity to think about dying and death as a part of life, and to create circumstances in which tens of thousands of people undoubtedly have been able to die better than was once possible. Rereading Kubler-Ross's book after 30 years was a daunting experience. What could I possibly add to the wisdom and humanity of this moving and profoundly insightful work? And yet, I think there is more to say.

The model of a good death which this work has generated, of last weeks, days and hours attended by thoughtful and experienced professionals able to tolerate and think about intense emotional pain, help those close to the dying person achieve something of the same, while physical pain is also skillfully moderated – this it seems to me remains an experience available only to a few, and not only because of the limited resources we have to offer such care. The danger is that we idealise this rather privileged notion of 'a good death' and take false comfort from our unfamiliar position at the top of this league table.

### **Death is not an event in life – or is it?**

The inquiry into Mid Staffordshire NHS hospital trust, the Francis Report (2010) exposed standards of care for the ill and the dying that seem truly appalling, but which I suspect surprised fewer of us than it shocked. Anyone who in recent years has been an inpatient in a hard pressed general hospital might have some inkling of how and why matters could deteriorate to the degree that was revealed by Francis. But the mystery of how and why so much neglect, insensitivity and even cruelty, could become routine and normalized has not been solved, at least not to my satisfaction. The solution is obviously complex, and I mainly want to address just one dimension in what follows.

In summary, our relationship to death poses us with an extreme instance of something more general and familiar to anyone who works in the field of mental health or social care, namely how hard it is emotionally to keep moving towards rather than away from intense mental pain and anxiety, and how correspondingly hard it is to create and maintain organizational systems that support this simple but exceptionally challenging task.

The philosopher Ludwig Wittgenstein once wrote, 'Death is not an event in life: we do not live to experience death'. This seems right, and I suggest most of us are terrified of death because we do not want to stop living, not because we fear what lies beyond death. But of course death is an 'event in life' for all those left behind, and so the idea of a good death is, I suggest, all about how to live in relation to others *as we are dying* and how those of us close to the dying live and relate to the dying *as they are dying*. Perhaps the phrase 'a good death' subtly shields us from this, to me more challenging but also realistic formulation. Also, the question arises 'for whom is a good death good?', the dying person or those attending, and destined to survive, and can the one find accommodation with the other?

As I prepared this paper, it gradually dawned on me that there are just so many ways to die, and also so many ways in which our own mortality, and that of others, may impinge on us during the course of life. Another philosopher, Spinoza, wrote that 'A free man thinks of nothing less than of death, and his wisdom is a meditation upon life, not upon death' (Spinoza, 1996). In my early twenties I wrote a long post-graduate thesis about Spinoza, and inscribed this quote on the cover of a green A4 notebook I kept. During this period I was also ill with Hodgkins Disease, a life threatening but even in those days treatable cancer of the lymphatic system. I survived, and indeed also survived a recurrence a few years later. I still think Spinoza's words are wise, but I also presume it was no accident that I selected this proposition from his *Ethics* rather any number of other choice observations, for my notebook cover. Death and dying were very much on my mind, whatever reassurances I was receiving about my prognosis. My first published paper, in the *Lancet*, was an account of my experiences as a Hodgkins patient, and I wrote there

that 'To the oncologist a 90% survival rate may look pretty impressive. To me as a patient it looked more like a one in ten chance of dying very soon.' (Cooper 1982)

Sooner or later then, death, our own mortality, forces itself upon our attention. I was unfortunate to have to wrestle with this so young, but eventually nearly all of us will confront this state of affairs. The exceptions, I suppose, include those of us who drop suddenly and unexpectedly dead from a brain hemorrhage or heart attack, or similar - it happened to my young son's football coach, a vigorous, energetic man in his mid-40s, and to my own older brother when he was 58. A few among us may die suddenly and violently in road accidents, plane crashes, terrorist attacks and the like, but a greater proportion of us will die after suffering a lengthy dementia of some kind that will rob us of most of our psychological agency in relation to our dying.

**'Cold, stone coloured, like marble...'**

For all these reasons, and more, the question mark in the title of this paper became for me its focal point. So I want to borrow from one personal experience of a very different kind of death, to remind us that for many death and dying just does remain unpredictable, uncontrollable, and unthinkably painful.

Some years after the death of her 19 month old son Joe, Denise Turner carried out systematic qualitative research with parents who had experienced sudden, unexpected infant death. Her own experience, skillfully and sensitively mediated, lies at the emotional root of this work, and of her own researcher sensitivity, and here she tells the story of finding her son dead. Joe was one of twins, born prematurely, and he had always been vulnerable to colds and chest infections but Denise had been reassured that this was nothing serious.

*One Sunday night in March 2005 Joe seemed a bit snuffly. I took his temperature which was normal, checked for signs of a rash and reassured put him to bed as usual. He drank a good bottle of bedtime milk. Colds were very common and because I had been told Joe was a 'Happy Wheezer', I was not unduly concerned.*

*In the morning, Amy came into bed with me before I went downstairs to get the boys their milk; she went in to say good morning to them. When I walked into the room a few moments later, she was sitting in Dan's cot reading to him. Joe was lying face down in his own cot. "Joe's still asleep Mummy" she said. I took one look at him. He was cold, stone coloured, like marble. I knew immediately that he had been dead for hours. The moment is frozen in my mind like a still from a film. It is one of those moments that perhaps most parents rehearse in their heads, hoping it will never happen and wondering what they will do if it does? What I did was to get Amy and Dan out of the room. Joe was dead. There was nothing I could do for him. My instinct, in that second was for my two living children. "Yes," I said, "Joe's still asleep. Let's not disturb him" And I settled them downstairs. (Turner 2013, 26-7)*

A central theme of Denise Turner's research is the impact on parents and other family members of the policy led professional response to a death of this kind, known as a rapid response protocol. Almost within minutes of alerting services, her home became a crime scene, swarming with professionals, and the body of her son became the legal property of the coroner.

*'Part of me anticipated the moment of my arrest and the removal of my two surviving children. Like Davies (2010, p. 7) I felt 'undermined, disbelieved and threatened', propelled by random tragedy into a world of police investigation and forensic evidence where I was a suspect in my own home, only minutes after finding my son dead in his cot. (2013, 29)*

Later she reflects:

*...one of my lasting impressions of Joe's death (is that)... most of the professionals involved were having a terrible time. No one seemed genuinely able to cope. The horror of the situation, the fear of being held culpable and the sheer randomness of the death seemed to immobilize people's basic humanity at this most human of times. (2013, 32)*

Implicitly, she links these observations to what subsequently ensued::

*What did surprise me (however) was that hardly anyone came. The G.P called briefly that night to check on Dan. After the tidal wave of professionals who filled our home*

*that morning had dispersed, we were left in the weeks that followed to cope with our two surviving children; the shock of Joe's death and the surrounding events, as well as the countless tasks that follow a death, with almost no support. (2013, 30)*

### **Dying in 21<sup>st</sup> Century Britain**

This story points up certain paradoxes about death and dying in 21<sup>st</sup> century Britain. Concurrent with the progress we have made in creating authentically responsive and caring spaces and places in which to negotiate dying and death, we have also bureaucratized, proceduralised and protocolised death. Controversies over the so called Liverpool End of Life Care Pathway are a manifestation of this tension. This reflects the experience of mental health and social care works more generally, that they aspire all the time to work in close relationship with people, but find themselves constrained by the requirements of statute, policy, procedure, guidance, protocol and performance management regimes to operate in a perfunctory manner that meets organizational needs but neglects the lived experience of service users. It is too simple to explain this bureaucratizing trend as a just another variety of 'social defence' against the anxieties of death and dying or other forms of mental pain, the organizational normalization of professional practices that distance people from the pain of the work, as described by Menzies Lyth in her classic paper about general nurses in a general hospital (Menzies Lyth, 1959). But Denise Turner's experience of immediate, intense, but also institutionally suspicious professional responses succeeded by prolonged neglect of her emotional circumstances suggests a dynamic in which we may move towards dying and death when compelled to do so, but too often in a spirit of anxious mistrust, only then to flee the scene leaving the bereaved entirely 'dropped from mind'. While perfunctory and routinized responses to the lived experience of a dying or bereaved person may be conveniently and unhelpfully *supported* by organisational cultures of procedure and risk aversion, such responses will emanate as much from our own deep anxiety about how to really 'be with', or stay alongside, people traversing dying and death.

### **My father, his father, and me**

So also when I was in my in my twenties, my father died after a long dementing illness. I had a lot of difficulty communicating and relating to him through this period, as did all his family I think, and he was not a man who was ever comfortable with

strong feelings or emotional pain. But one evening as I sat quietly and anxiously with him he suddenly said to me, 'I wish I could die like my father did. He sat down after lunch one day, had a heart attack and died just like that'. It was the most poignant and painful communication my father ever made to me. In the midst of his suffering and disorientation, I think my grandfather's death became my father's idea of a good death. I cannot be sure, but I now suspect that my father was just appallingly lonely during these last years, exactly because no one around him could bear, or could summon the emotional resources, to find a way to come closer to him.

The sociologist Clive Seale speaks of dying people 'falling from culture' (Seale 1998) as they become more dependent and unwell in the period, sometimes lengthy, that precedes death, as they lose connection with the networks and routine relationships that are the taken for granted social tissue of our aliveness. Thus what he calls 'social death' may often precede the death of the body. It is family and perhaps close friends who are there, or not, to accompany the dying person in their final period of life, and a disproportionate burden of this task falls of course to women. The emotional task of truly 'being with' someone as they approach their death, so that they do not experience themselves as 'dropped from mind' by those closest to them, is perhaps one of the greatest tests of emotional maturity that any of us will face.

I felt hopelessly inadequate in the face of my father's process of dying, and guilty for many years afterwards. Eventually it was a relief to let go of any ambivalence I felt towards him as my father, and say to myself, 'I wish I had been able to be a better son to you'. But in writing this paper, I came to a slightly different view of matters. His communication to me, and my receipt of it, was not nothing. Out of the silence, the void that I remember him apparently inhabiting much of the time as he deteriorated, he was able to formulate this expression of his distress, in effect of his wish to die and be released, and deliver it to me. And I was at least there to receive it. There could have been so much more, but I suspect that even such a fleeting moment of connection as this is hard won by all involved. Maybe there were other moments with my mother or other family members, I don't know. We just didn't talk properly about it. But I offer this story, and these thoughts, to provide us with some sense of the difficulties that face us as we try to think well about this idea of 'relating to dying' – what we might hope for as we ourselves approach death, and what we

might hope for from ourselves in relating to others in their dying. And finally, recognizing the depth of the emotional challenge involved, the value of forgiveness for what we fail to achieve with others, or to receive from them.

This is the territory explored by Atul Gawande (2014) in his profound and important book *Being Mortal: Illness, Medicine and What Matters in the End*. In the space that lies between manic hope or denial, and helpless resignation in the face of the knowledge of imminent death, Gawande describes the 'hard conversations' the dying and the living need to have, so that the dying person can exercise maximum feasible choice about how they spend their last weeks, days and hours. Medicine has become heroically addicted to prolonging life at all costs, disabling everyone's ability to weigh the balance between longevity and quality of life in the final phases of living. 'Assisted living is far harder than assisted death, writes Gawande, 'but its possibilities are far greater as well'. ..Our ultimate goal, after all, is not a good death but a good life to the very end' (2014, 245).

## **Beyond death**

Some people and families do manage what we might all think of as a good death, or a good life to the very end. I have witnessed it and I expect many readers have as well. If I have dwelt on the challenges and impediments to dying well then that is because I suspect that 'good deaths' remain the exception rather than the rule, even in our supposedly advanced society. There is a school of thought and practice, best represented maybe by the British Humanist Society, that tries to approach death and dying rationally, free from illusions about an afterlife or salvation of the soul, but nevertheless deeply respectful of our need for meaning in relation to death and loss. I think Spinoza's stance – cited above - is consistent with this ethos. Death and dying take their meaning from life, and the deep mourning that attends the loss of life, whether imminent or actual. The terror of this loss, the ultimate loss, at once evoking and transcending all other losses we have experienced, is what renders dying so hard to bear.

I think the existential reality is that we each die alone. No one can do it for us, and no one can accompany us in death itself, only on our passage towards it, or if we are



the survivor, following it. But this is not the same as dying in a state of loneliness. In a secular way of thinking, our salvation, our after life if you prefer, resides in the possibility of being remembered and held in the minds of others long after death. In this respect I offer another short extract from the autobiographical writing of another researcher into modern experiences of dying. Here she is recalling her father's death.

*On the night he died I was at home with my children. My husband was out and the friend I had spent the evening with talking about my father, stayed so that I could go by taxi to my parent's home within a few minutes of his death. When I arrived I was able to help my mother wash him and get him ready to leave his home for the last time. It is difficult to fully describe just how much being able to perform this ritual meant to us both. It was at the time, and remains now, one of the most significant things I have ever done. It felt completely right and appropriate, and something that we could do for him before we had to let him go. It was a way of beginning to love him beyond life. (Scanlan, 2014)*

To know, or to echo the Christian form of words, 'to have a sure and certain hope' that we might be loved, remembered and cared for in our afterlife in such a manner might be the nearest we can approach to answering the probably universal need for a 'good death' – that which we all hope for, but may or may not be granted.

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Address for correspondence: Andrew Cooper, Adolescent Department, Tavistock Centre, 120 Belsize Lane, London NW3 5BA. [acooper@tavi-port.nhs.uk](mailto:acooper@tavi-port.nhs.uk)

Andrew Cooper is Professor of Social Work at the Tavistock Centre, London. This paper is based on a talk given at The Institute of Classical Studies/Tavistock & Portman NHS Foundation Trust Symposium, 'A Good Death?' October 28<sup>th</sup> 2015

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