'IS THERE SUCH A THING AS A GOOD DEATH?'
IF SO, 'WHAT DOES A GOOD DEATH MEAN?'

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Is there such a phenomenon as a good death? Obviously, debate over whether people are dying badly or well depends on what a definition of a good death is. Yet, a clear understanding remains difficult to define as the experience of dying is as varied as it is complex. How do we conceptualise what a good death represents when the breadth of experiences relating to dying are so multifarious? In addition, the determination of a quality death is both intrinsically subjective to the dying person and their loved ones; dependant on presenting circumstances; or, often ascribed by the medical fraternity. The facts are that the processes and experiences surrounding death and dying are complex, and challenging. The term "good death" in itself is limited to the dualistic notions of "good and bad" - an either/or experience – one experiences a positive or, a negative death. This is a philosophical and spiritual conundrum. Perhaps a more appropriate description relating to the quality of the dying experience would utilise the following terms: ideal, satisfactory, meaningful, peaceful, enriched, qualitative or, even "doing death well". What equates to a quality death experience can be informed through philosophical, spiritual, psychological, physical, medical, cultural and social nuances. Often dying amounts to an information processing problem – too many issues and not enough time to come to terms with them.

I have heard many people say that dying in one's sleep would be the ideal death. This might well be so in some cases but when considering all contingencies, a sudden or unexpected death often does not prepare the dying person or their family and friends for the inevitable aftermath. It gives the incumbent no chance of putting their affairs in order (if they haven't done so already); it provides no possibility of goodbyes or resolutions and it denies preparedness both for the incumbent and those left behind. Doing death well is such a subjective experience and must cater to the individual's wishes, the

medical imperatives, the prevailing environment, the practicalities and the physical and mental state the person is in. One could say that the expectations around death are akin to those around childbirth. We often have our ideal, but the reality frequently does not match it. Plus, what we aspire to in regards to how we die – whilst we are alive and well (for those of us who do contemplate the subject) – often becomes a different scenario when we are faced with the cold hard inevitability of our own demise. So, we tend to

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have a dissonance between what is decided upon intellectually as an ideal and what the person's actual emotional, spiritual, practical and physical requirements are when the time comes. Some things, like the ideal of dying at home, are simply not possible due to circumstances beyond everyone's control.

In recent years, there has been an increase in studies examining what it means to have a good death. In a 2000 study, Steinhauser et al identified six major components of a good death: pain and symptom management, clear decision making, preparation for death, completion, contributing to others, and affirmation of the whole person. The six themes were seen to be process-oriented attributes of a good death with each having biomedical, psychological, social, and spiritual components. Physicians offered the most biomedical perspective, and patients, families, and other health care professionals defined a broad range of attributes integral to the quality of dying. An Australian study examining the experiences of cancer patients in their final year of life identified the key features of a good death as being: 1) the social life of the dying; 2) the creation of open awareness; 3) the social adjustment to and personal preparation for death; 4) the public preparations such as arrangements relating to work; 5) the final farewells. In the author's view, a good death was one which involved a great deal of social interaction (Kellehear: 1990).

Henwood & Neuberger (1999) in their final report on The Future of Health and Care of Older People identified 12 principles of a good death. These appear to be beneficial but ideal principles and would be a positive addition to the plans of individuals and families, professional institutions and health services.

They are as follows:

1. To know when death is coming, and to understand what can be expected
2. To be able to retain control of what happens
3. To be afforded dignity and privacy
4. To have control over pain relief and other symptom control
5. To have choice and control over where death occurs (at home or elsewhere)
6. To have access to information and expertise of whatever kind is necessary
7. To have access to any spiritual or emotional support required
8. To have access to hospice care in any location, not only in hospital
9. To have control over who is present and who shares the end
10. To be able to issue advance directives which ensure wishes are respected
11. To have time to say goodbye, and control over other aspects of timing
12. To be able to leave when it is time to go, and not to have life prolonged

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pointlessly

Of course, there are some situations where the dying person and their extended family and friends are swept away by the presenting conditions – an aggressive recently diagnosed cancer, an accident, or a sudden unexpected illness. There are situations that are simply traumatic and the dying person and the people around them are so overwhelmed that no amount of preparation or idealism can prevail. In these circumstances, no one has the prescience, time to contemplate or enact any of the elemental principles deemed to be complimentary to a good death. There are also certain dying individuals who by nature are stoic, stubborn and uncommunicative. They may choose to deny or not discuss the fact that they are dying and this fact must be respected. Not everyone is willing to examine the fact that they are dying and many refuse to acknowledge it or, talk about it. People cannot be coerced so, it is then left to the health care team, family or friends to enable a smooth transition whilst simultaneously accepting the person's state of being.

In another study published in the American Journal of Geriatric Psychiatry, which gathered data from terminal patients, family members and health care providers, the researchers aimed to clarify what a good death looks like. The

literature review identified 11 core themes associated with dying well, culled from 36 studies:

- Having control over the specific dying process
- Pain-free status
- Engagement with religion or spirituality
- Experiencing emotional well-being
- Having a sense of life completion or legacy
- Having a choice in treatment preferences
- Experiencing dignity in the dying process
- Having family present and saying goodbye
- Quality of life during the dying process
- A good relationship with health care providers
- A miscellaneous "other" category (cultural specifics, having pets nearby, health care costs, etc.)

When considering the nature of dying well it appears dependant on the extent to which people are accepting of the impending death and whether they receive adequate emotional care and support which meets their individual needs. These factors can mitigate the dying person's discomfort and reduce any trauma. On a personal level when addressing what a good death means to me, I would prefer to couch the term as my

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most ideal death. That would be one in which the following applied:

- To have total transparency and truth telling between all parties involved
- To have adequate preparation and be fully cognisant of the situation
- To have access to and be informed of all medical information and expertise
- To have personal empowerment, support and respect in my decision making
- To have access to any spiritual care that I may require
- To have no unfinished business in any area of my life
- To have no unresolved conflicts or issues with loved ones, friends or acquaintances
- To have everything my heart desires to accompany me on my journey. Meaning: music, incense, loved ones, poetry, spiritual mementos, oils & balms, loved animals, art, pictures and any other materials etc.
- To not be 'over medicalised' and to be kept fully informed by all parties
- To have my end of life and post death wishes unequivocally respected and followed
- To die as consciously and mindfully as possible. To be able to feel the processes and be aware of my journey
- To be spoken to and read to even if I am unconscious; that I am related to just the same – alive or dead
- To be kept as comfortable as possible without inducing delirium. Life isn't pain free so I don't expect to die pain free!
- To die with no regrets – to be complete – to have closure
- To have people around me – including family and friends be selfless and behave themselves!

Ultimately, it may be that the amount of baggage a person carries with them at the time of death – their ideas and emotions - determines the quality of their death. It may be dependant on the quality of their relationships, their self honesty and their skills development over a lifetime. However, when we are talking about what constitutes a good death, we are talking about an ideal and most of the principles discussed are predicated on having forewarning and preparation time. Having said that, I would presume that the majority of people will live to an older age, dying mainly of age related infirmities and therefore have ample preparation for their death – if they so desire. The pain people experience from their past often follows them into death. The bottom line is that each and everyone of us is responsible for our individual approach to death. We must do our inner work and cultivate insight into ourselves. Breaking the death "taboo" in western society by incorporating discussions about death in everyday life would open the pathway to seeing death as a natural process – to be revered but not feared. Open awareness may well contribute positively to the way each individual approaches his/her own death and accordingly, enhance the dying experience. It is a common Buddhist saying that we are all of the nature to get sick grow old and die. It is probably just as

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well that we have no knowledge of exactly how and when.

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