



A Good Death

Megan Best

Harry was what you might call a rough diamond. He had a good heart but didn't always find the words to express what he felt inside. He came into our palliative care unit to die. He knew he was dying, and he wasn't so much scared of dying as unsettled by it. He found it difficult to cope with the symptoms caused by his cancer. You could say he was suffering.

Many studies have examined what it is that contributes to what is widely known as a 'good death'. The term was used by euthanasia advocates in the 1960s and 1970s, often as a protest against life-prolonging measures that were becoming more common with the widespread introduction of life-sustaining medical technology. A few high-profile cases, such as that of Karen Quinlan in the United States, focussed protest against interventions that left comatose individuals wasting away on life-support machines long after their quality of life was gone. This may explain why the turning off of life-prolonging treatments has been confused with euthanasia, but this is a misunderstanding of what is happening when we flick the switch.

Life-support is introduced as a trial therapy to support a patient long enough to enable them to recover from underlying illness; if withdrawal of life-support leads to death, it is not the act of withdrawal that kills them, but progression of the underlying condition. Similarly, if treatment that was originally aimed at increasing survival is found to no longer work (it is futile) or becomes so burdensome to the individual that the benefit is no longer worth it, ceasing such treatment is not euthanasia for the same reason. Sometimes we confuse prolongation of life with prolongation of the process of dying. No one wants that.

Even if an individual decides to forgo the potentially life-prolonging effects of treatment, for example anti-

cancer therapies, that is a completely ethical and legally permissible option.

No competent adult has to accept treatment they don't want. No biblical maxims insist that we should do all we can to prolong life. To do so would be to treat life itself as an idol. We all have to die of something, and if you have had a good life and are ready to meet the Lord, it is okay to let go of life and let the disease run its course.

But Harry is suffering. Is he a classic case for euthanasia?

Well, he hasn't mentioned it at this stage. Requests for euthanasia are quite unusual, and we who work in palliative care find they often are dropped once care has started. Palliative care is a relatively modern specialty, developed in the 1960s in the United Kingdom by Dame Cicely Saunders. Its aim is to improve the quality of life of patients and their families who are facing life-threatening illness, through the prevention and relief of suffering by means of early identification, impeccable assessment and appropriate treatment of pain and of physical, psychosocial and spiritual problems. According to the World Health Organisation, palliative care:

- Provides relief from pain and other distressing symptoms.
- Affirms life and regards dying as a normal process.
- Intends neither to hasten nor postpone death.
- Integrates the psychological and spiritual aspects of patient care.
- Offers a support system to help patients live as actively as possible until death.
- Offers a support system to help the family cope during the patient's illness and in their own bereavement.
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated.



- Will enhance quality of life, and may also positively influence the course of illness.
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.¹

More recently, clinicians caring for patients at the end of life have started to explore the term 'good death' more literally, with careful questioning of patients, families and health care workers, trying to ascertain what would contribute to a peaceful and meaningful end of life experience for them.

A review of the literature in 2006² found that the most important thing to realise about a good death is that it will differ for each individual, as it is influenced by the patient's perspective and experience. Furthermore, it is dynamic, that is, it can change over time. Facilitation of a good death will require ongoing dialogue with the person involved, without preconceived ideas of what they will say.

So what could we do for Harry? He was in pain, and required morphine in regular doses to control his symptoms. However, he was hesitant to start the recommended treatment. This is not uncommon in palliative care, as myths about morphine are rife in the community. One myth is that if you take morphine for pain you are at risk of addiction, yet this is in fact very rare in those who take morphine for pain - and the one case I have seen had been addicted earlier in life. Another myth is that morphine will shorten your life. This myth has been promoted by the euthanasia lobby, who suggest that, as (they say) pain medication and sedatives used for symptom control shorten life (which they call 'passive euthanasia'), why can't we just let someone die sooner by direct lethal injection (which they call 'active euthanasia'). You see the problem. In reality, there is much research showing that therapeutic doses of morphine and other drugs do not shorten life, and may in fact prolong life, probably because the patient is more comfortable. We who work in palliative care know how to use these drugs without overdosing our patients accidentally. We only use the dose needed to control the symptoms. Comfort is the goal.

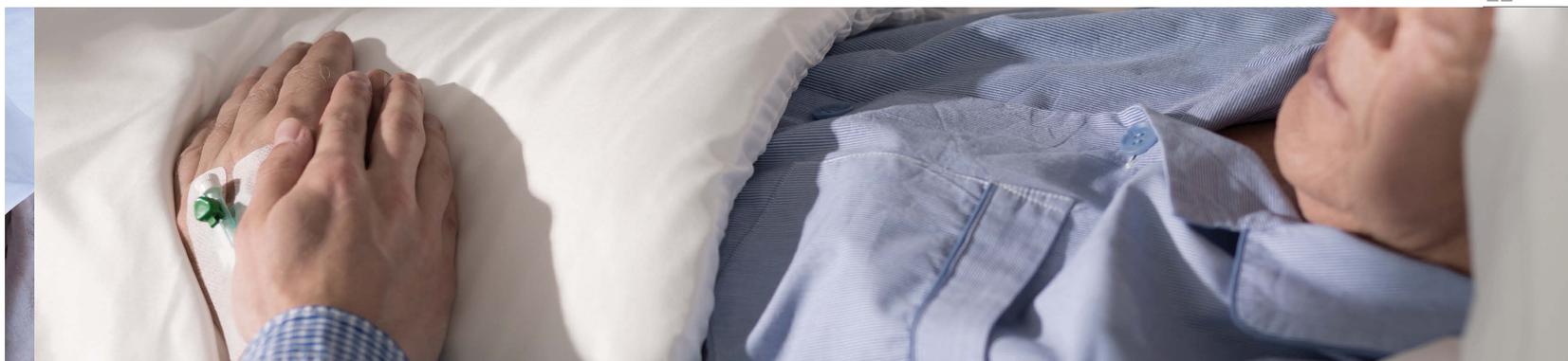
Eventually, Harry is persuaded and treatment is started. The pain control improves but there is still something not quite right. Late one day I go into Harry's room and we have a chat. We are old friends - I have been seeing him in the clinic for over a year and I know he trusts me. Early referrals to palliative care allow us to build relationships and enable us to support our patients better, and doing

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this has been shown to increase survival in lung cancer patients.³ I ask what is important for him now that his time is short, and he talks about his family. It turns out that Harry has never told his sons how much he loves them. They haven't been close for many years and he hasn't told them he's in hospital this time. We talk about how Harry would like to be remembered by his family. I tell him he's doing really well, and leave him to it. It could have been another team member, such as a nurse or a chaplain, who had this conversation. It doesn't really matter, so long as someone does it.

Despite the individual nature of end of life preferences, there are some attributes of a good death that remain constant across populations.⁴ Being in control, being comfortable, having a sense of closure, value of the dying person being recognised, trust in care providers, recognition of impending death, respect for the individual's beliefs and values, minimisation of burden for the patient and their family, optimisation of relationships, appropriateness of death, leaving a legacy and family care are reported to be associated with a good death.

There are many ways one can be in control at the end of life. The media focuses on a self-chosen death as the only way to have control, but that is not the experience of most people actually facing approaching death. It is also possible to be in control by communicating your wishes to those who care for you and by having them respected. Our federal government is investing in initiatives that promote advance care planning, a process whereby we can discuss with our health care providers the type of treatment we would or would not want if we were unable to express our wishes at the time. You can choose which people you want present, and where you would like to be in your final illness, as other important ways of retaining control. Harry had initially wanted to die at home, and we had arranged community support to facilitate this. However, as the time got closer and his nursing requirements got more complicated, Harry decided he would rather be in the palliative care unit with staff on call around the clock. This is one way the concept of a 'good death' can change, and



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we respond as well as we can.

Being comfortable is also important for a good death. This obviously includes physical comfort, though interestingly not everyone wants to be completely symptom-free (perhaps due to cultural or religious beliefs). It also includes emotional and spiritual well-being, the latter being as important for quality of life for cancer patients as physical well-being. Hence the need to enquire about spiritual needs, such as retaining a sense of meaning and purpose, even when time is short.⁵ Spiritual care should not be confused with religion, which is a subset of wider community spirituality. While religion and making peace with your God will constitute the spiritual work of some people, it is not the universal spiritual framework. Tasks of the dying include getting a sense of closure by acts such as saying goodbye, completing unfinished business and preparing for death. It always astounds me that both family members and healthcare workers can hesitate to let an individual know when they have life-threatening illness and don't have long to live. Such information is a gift and very valuable to the person involved, allowing them to do the important things while they still have time.

An interesting aspect of spiritual intervention is that palliative care workers are not the ones who do the work. When it comes to spirituality, we each have to find our own way. However, there is no doubt that palliative care workers see patients 'pick up the bat and ball' after the initial encouragement to address these aspects in their lives. Often, part of this encouragement comes in the form of affirmation of the individual, by letting them know that they matter even if they are sick and unwell. Too often in our society we judge others by what they can do. This demeans those amongst us who are less capable. To be recognised as a whole person is to treat a human being with the dignity they deserve as one made in the image of God.

Harry has contacted his sons and they're coming in on the weekend. He is nervous but excited to see them. As palliative care considers the family of the patient part of the care unit, inpatient units tend to have flexible visiting hours, and often family can stay overnight if desired. Whatever our community has to say about the primacy of

autonomy, we know that we are embodied souls who live in relationship and we cannot understand our situation in isolation. No man is an island.

When I come in the next week I can see that Harry is more settled, even before I hear the nurses' report. Later I hear that his time with his sons went well and that he was able to tell them how much he cared. We often find that, when spiritual well-being is addressed, the physical follows. All dimensions of an individual can impact on others and we need to care for the sick in a holistic way to ensure we address all issues of concern.

Harry passes away peacefully several weeks later, having met with his sons on two further occasions. It is a peaceful death, and I think he and his sons would have said he had a good death. He had lived until he died, and left no unfinished business. That was what he wanted.

The palliative approach to care is recommended for all doctors caring for dying patients, that is, one where the goal of treatment is comfort rather than cure. Not everyone will need the care of a palliative care team to have a good death, but it can sometimes help. One of the biggest gaps in Australian health care today is adequate specialist palliative care provision for those who need it. Currently, specialist palliative care services are involved in the care of less than half of Australians at the end of life.⁶ Minority groups, children, private patients, and rural and remote communities miss out most. Surely we can do better.

Endnotes

1. C. Sepúlveda, A. Marlin, T. Yoshida & A. Ullrich, 'Palliative care: the World Health Organization's global perspective', *Journal of Pain Symptom Management*, 24 (2), 2002, 91-96.
2. K.A. Kehl, 'Moving Toward Peace: An Analysis of the Concept of a Good Death', *American Journal of Hospice and Palliative Medicine*, 23 (4), 2006, 277-286.
3. J.S. Temel et al., 'Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer', *The New England Journal of Medicine*, 363 (8), 2010, 733-742.
4. K.A. Kehl, 'Moving Toward Peace', 277-286.
5. M. Best, P. Butow & I. Olver, 'Creating a safe space: A qualitative inquiry into the way doctors discuss spirituality', *Palliative Support Care*, 2015, 1-13.
6. Australian Institute of Health and Welfare, 'Cancer in Australia: an overview', Cancer Series No. 90, Canberra, AIHW, 2014, Contract No.: Cat. no. CAN 88.



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