Palliative and Supportive Care

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A good death

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Essay/Personal Reflection

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Author for correspondence: Alexander Hayes, King's College London, Faculty of Life Sciences and Medicine, London SE1 1UL, UK. E-mail: alexander.hayes@kcl.ac.uk To state an under-discussed truism: we are all going to die, and not every death will be a "good" death. Through discussion with the daughter of a patient who died, and the medical team who cared for her, I have learned how a good death can better lives.

Alice*, a woman in her late 70s, was admitted to an orthopedics ward at a busy hospital, for the surgical management of a femoral dislocation. The dislocation had left Alice bed-bound, and the procedure aimed to mitigate the pain that she felt when trying to mobilize. Alice had previously been living in an independent living unit and had multiple comorbidities. Throughout the preceding 4 years to this admission, Alice had been in and out of hospital, and her health had been in gradual decline. Alice's daughter Beth* was present throughout this hospital admission.

Over the course of Alice's admission, her health declined, and she was recognized as someone who may be approaching the end of life. Owing to a complex medical history and symptom profile affecting Alice's capacity, a "best interests" meeting was called. Here, team members and Beth agreed that the right thing to do was to cease medical treatment and to keep Alice comfortable in the hospital until she died. This was consistent with Alice's prior declared capacitous wishes.

Approximately two weeks after the withdrawal of medical treatment, Alice died peacefully in the company of Beth, who described it as a "beautiful death."

I never met Alice; I only came to hear of her story after she had died. This was my first professional exposure, albeit indirect, to death. I had been told that this was a "good death," and I wanted to understand what that meant. Beth wanted to tell her mother's story so that others could learn from it, telling me that "If everybody could experience a death like that for their loved ones, then the fear of death would be removed."

After asking Beth and the team members what made a death "good," two prevailing themes emerged. First, the early recognition that someone is dying, and the honest communication of uncertainty in that process. Second, a compassionate approach to health care.

Beth explained why she believed effective communication around the end of life was so important. Beth recalled a conversation that proved to be of paramount significance throughout her mother's care. In the presence of her mother, a team member asked: "Do you want me to talk honestly to you, Beth?" Beth said "Yes." This conversation was regarding Alice's prognosis, potential treatment plans and the fact that she was at risk of dying. Staff informed Beth that if not receiving medical treatment, Alice would likely die within 10 days. Crucially, Beth said that the staff emphasized that the withdrawal of medical treatment in no way entailed the removal of care. Beth affirmed that this open conversation removed the "elephant in the room" and paved the path for the acceptance of death. Alice's prognosis had not been altered, but this early and honest conversation intended to empower Alice, so that she could express her wishes and die on her own terms.

The recognition of those who are at risk of dying is a formidable and complex task and is not an exact science. Moreover, simply recognizing and accepting death doesn't guarantee an uncomplicated dying process. Team members, with the assistance of specialist nurses and the Palliative Care team, recounted difficulties in controlling Alice's symptoms. Beth too noticed times when Alice felt pain upon daily activities, such as washing: "Horrible times when Mum was in pain and the staff were trying... tough times." In the face of the uncertainties of our understanding of the process of dying and optimal pain management, Beth was unequivocal about the commitment and compassion of team members when caring for her mother. Beth detailed her final conversation with a doctor, in which the sole purpose was to make sure she understood that Alice was dying. Beth recalled the safe feeling of the environment: "It was at that moment when I knew everything was going to be ok."

Team members reported that they were working within the limitations of current clinical practice, knowing all they could and doing all they could, for Alice. Beth, however, went further in describing the impact of their work, recounting the memory of a nurse who acted as her mother's advocate in the "best interest" meeting. The nurse summarized and understood Alice's wishes meticulously. Beth praised the ability of the staff to listen, make time for them and communicate everything as it happened. In spite of clinical limitations, Beth did not feel their care was remotely limited.

Beth reflected upon the juxtaposition of a patient who is receiving end-of-life care residing on a surgical ward, a place where many recover and walk out with tangible recoveries. Beth commended

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the continuation of care that staff members provided to her mother, even in this busy environment: "Never once forgetting that she was a person." Staff members continued to speak to Alice even when unconscious, and Beth commented on the ubiquity of care and love in each component of her mother's care. Ultimately, she lauded their professional credo, stating that her mother was "a person and that this was another stage in her life." That she was going to die, everyone knew it and that everything would be ok.

Every year, we celebrate our birth, but think of death only when forced to. The COVID-19 pandemic has forcibly thrust death onto the center stage, and for many, death's sting now lies close to home. An acceptance of death may come too late, our tardiness can make patients', friends,' and loved ones' wishes sorrowfully futile. I have learned, however, that the experience of a good death can create ripples stretching far beyond the healthcare environment, helping to rewrite the narrative of death.

Death, by its very nature, is the eventual cessation of life. If we take it that living is good and that death is an evil, we can warm toward Thomas Nagel's belief: Death is evil not for the harm it gives to us, but in what it takes from us (Nagel, 1979). That is, what they could have done in the future, their potential, curtailed. Seeing death solely as this, it is easy to understand our reticence toward the subject. Beth detailed why she thought that some may be tempted to delay a conversation about death. She believed that the fear of a negative reaction regarding death prevents medical staff from talking about it. It could be argued that, for many, death is still seen as a failure of medicine, and to accept death is to effectively give up. If, however, we are to see death instead as a journey, then we can transform the idea of death for the better. This transformation necessitates early recognition, communication, and perception of death as part of life, which allows the

patient and their carers to dictate their wishes and steer the journey how they will, and what is reasonably possible.

When medical staff assist patients in dying a good death, they influence the collective psyche and help reclaim the term "death." As people begin to see death more as another step in their life journey, and less as a person's abrupt and scary discontinuation, it becomes an increasingly approachable topic. Utilizing a positive feedback cycle, as opinions outside of medicine favor honest conversations about death, medical staff may find it less of a taboo matter to discuss. Ultimately, the ethos of medicine — to help — may be best served by an early, open, and compassionate approach to death. I have been inspired by Alice's story, and I will try to follow its example in my future practice. I hope to help people live a good life and die a good death.

*Names have been changed to ensure that patient confidentiality is maintained.

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Reference

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