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Dying the Good Death

The Kate Granger Story

It was a cold, blustery day in 2004 when I visited my grandfather for the very last time at the VA Hospital in Manteno, Illinois. Always the professor, he spent most of his days at the nursing home facility "teaching" class to an imaginary group of university students while those around him made feeble protests or napped through the whole charade.

(Something, I reckon, only made for a more authentic atmosphere.)



On this day, however, he was not holding class, nor would he ever do so again. Instead, he was propped up in bed like a listless puppet, IVs poking in and out of his paper-thin skin leaving dark, nasty bruises in their wake. At the age of 84, my grandfather was dying, and I knew the moment I left the hospital, I would never see him again.

The way my grandfather died—in a clinical setting, hooked up to oxygen tanks, heart monitors and fluid drips—is a familiar one. However, it is very different from the way people died in the past.

When the Black Death swept through Europe in the 14th century, it claimed the lives of over 75 million people, many of who were clergymen whose job it was to help usher the dying into the next world. In response to the shortage of priests, the *Ars Moriendi* (Art of Dying) first emerged in 1415. This was a manual, which provided practical guidance to the dying and those who attended them in their final moments. These included prayers and prescribed rites to be performed at the deathbed, as well as illustrations and descriptions of the temptations one must overcome in order to achieve a "good death."



Ars Moriendi (15th-century copy) depicting men of all classes standing around an open tomb with rotting corpse in it; as well as Death and a pilgrim about to walk into an open grave.

From the medieval period onwards, the dying were

expected to follow a set of "rules" when facing the final moments of their lives, which included repentance of sins, forgiving enemies and accepting one's fate stoically without complaint.

As foreign as all this may seem to us in the 21st century, the concept of a "good death" is making a comeback today, albeit without the religious overtones. One such person who is trying to change the way we think about dying is <u>Dr Kate Granger</u>, a 31-year-old physician who was diagnosed with an aggressive form of sarcoma in 2011 and given less than 5 years to live.

Kate made headlines in British newspapers when she announced that she was going to tweet from her deathbed, using her own death as a communication tool for opening up discussions about mortality. Some of her hashtags—like #deathbedlive and #onedieseveryminute—may seem unnecessarily morbid, especially to those who are not used to engaging in conversations about death. But Kate believes her dark sense of humour has gotten people talking more openly about the fate that awaits us all.



Kate Granger

"Dying has become something we do hidden away within the clinical environments of hospitals and hospices rather than as it used to be, right in the center of that person's social context," Kate tells me. "Death is commonly viewed by the medical profession as failure." It is this "in combination with the technology available to us...[that] has led to a sense that perhaps we can overcome death in most circumstances."

Dr Granger—who specializes in geriatric medicine — readily admits that she is at an advantage when it comes to navigating her way through the medical system. Her decision to discontinue chemotherapy after receiving 5 rounds in 2011, for instance, was driven largely by her clinical background and her understanding that her type of cancer was ultimately incurable.

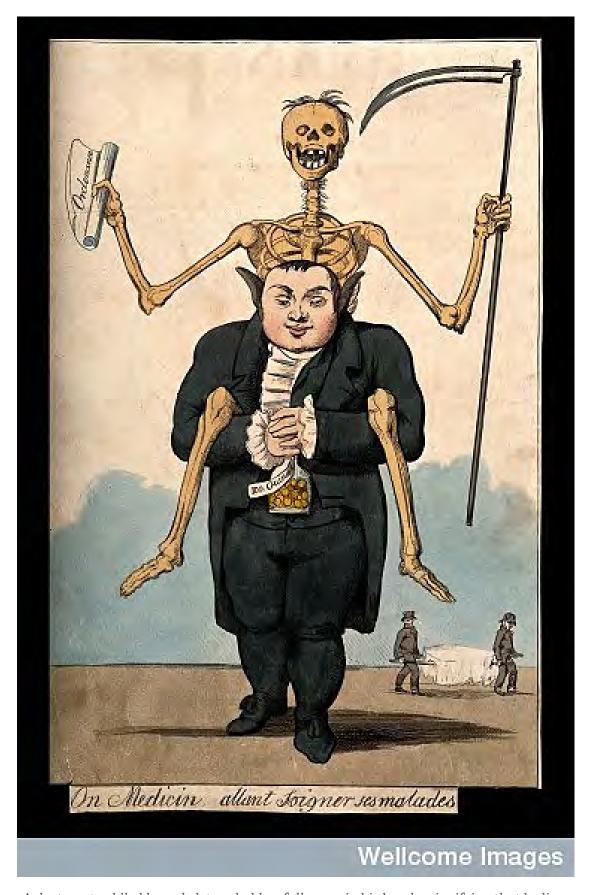
"Most patients just accept what a doctor tells them and comply," she remarks. "I wanted to make decisions that were based on what was best for my quality of life and not just do something because I was told to."

For Kate, it's about finding balance so that her final days aren't unnecessarily stressful: "I was finding going to outpatient appointments really distressing psychologically; the build-up to the appointment, the horrendously long waiting room waits surrounded by people at varying stages of their cancer journeys, what I call 'scanxiety' and the aftermath of having to carry on with life." For her, this was a "waste of both mine and my oncologist's time." She now emails him when she is feeling unwell.

In earlier periods, many people believed that pain was a

necessary component of a good death. Evangelical Christians, in particular, feared losing lucidity as death approached, as this would prohibit the person from begging forgiveness for past sins and putting his or hers worldly affairs in order before departing this life.

For this reason, the physician rarely appeared at the bedside of a dying person because pain management was not required. Moreover, the general consensus was that it was inappropriate for a person to profit from another's death. Caricatures depicting the greedy physician running off with bags of money after his patient had succumbed to his fate were not uncommon in the 18th and early 19th centuries.



A doctor, straddled by a skeleton, holds a full purse in his hands; signifying that he lives well off others' deaths.

Over time, however, religious sentiments faded, and physicians began to appear more regularly in the homes of the dying. Doctors also became more effective at pain management. At the start of the Victorian period, doctors typically administered laudanum drops orally to patients. This process was imprecise, and sometimes not effective at all.

This changed in the 1860s, when physicians started to provide their patients morphine intravenously. As new techniques emerged, people's attitudes towards pain management in treating the dying began to change. Soon, a painless death was not only seen to be acceptable, but also vital to achieving a "good death." The doctor's place at the bedside of the dying was now commonplace.

When I ask Kate about how she wants to die, she remarks: "I would like to be in an environment that smells familiar, that looks familiar and that isn't clinical." In other words, not a hospital.

"[I want] a serene experience, at my Mum and Dad's house where I grew up, with my husband, parents, brother and friends around me. My favorite music. My favorite films. Mum reading the books she read to us as children. Pain free. Other symptoms such as vomiting controlled. Alert enough to be able to interact. Candles. Laughter. Long enough to say goodbye, but not lingering too long."

This kind of death, however, presents its own problems in this day and age. "Planning is incredibly important if I am going to achieve my ambition," she admits. "Making sure everyone around me is aware of my wishes so they don't panic and phone an ambulance in the heat of the moment."

Until the 20th century, the home was the traditional location for death. Without the use of antiseptics or anaesthetics, admittance to a hospital could be a painful experience resulting in death even if the original complaint wasn't life threatening. Despite the proliferation of hospitals throughout the 19th century, people continued to choose to die at home.

As a 31-year-old woman, I cannot help but see myself in Kate. If faced with the same reality, would I be as graceful, as courageous, as dignified? Would I choose to die at home, or in a hospital? I ask the one question that has been on my mind since the start of this interview: are you afraid?

"I wouldn't be human if I said I wasn't frightened," Kate admits, "but I try to push fear to the back of my mind most of the time." Like anger, she does not think "fear is a productive emotion that is going to help me live my life day to day."

While fear and anger play little role in Kate's life these days, humour does. "I have a dark sense of humour" which

has become more apparent since her diagnosis, she confesses. It is a coping mechanism for getting through the day with this huge burden she must carry.

"It's amazing how infectious it is—I've got everyone around me cracking jokes about my impending mortality now too. I strongly feel openness is linked to acceptance in this sort of situation and that humour can facilitate that openness."

As for her goals and aspirations as she nears the end of her life? Dr Granger has many, from learning to speak Italian, to renewing her wedding vows and raising £100,000 for the <u>Yorkshire Cancer Centre</u> before she dies.

Above all, though, she wants her message to be heard by as many people as possible.

"I hope my involvement in discussing dying openly may demystify the fears that exist about death and will help other people to achieve better deaths."













