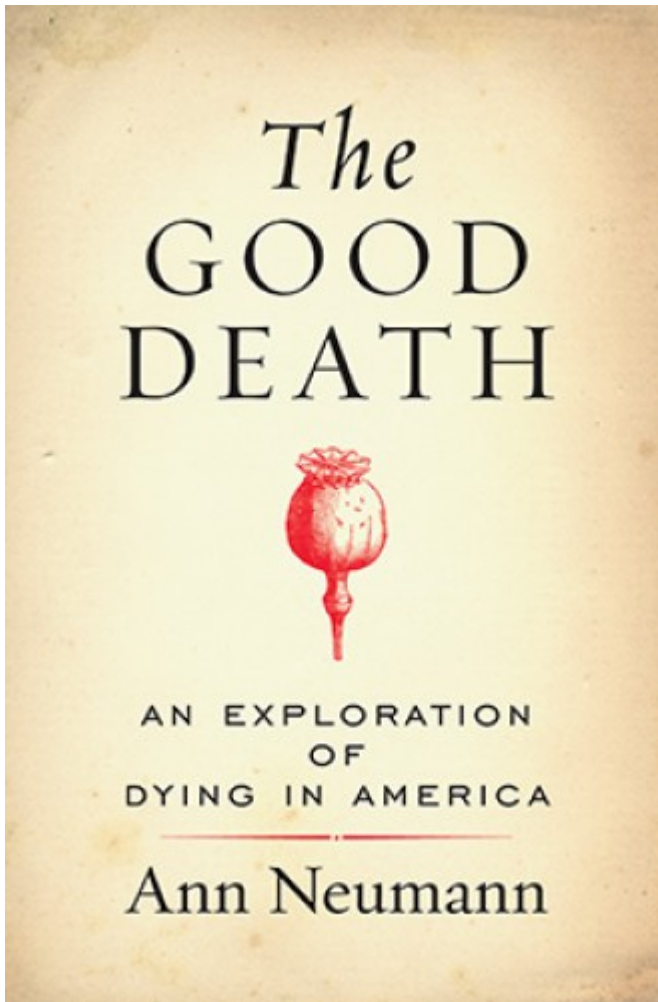


Bioethics and the good-enough death

## **Dying poses hard questions about autonomy.**

by [Sarah Moses](#) in the [January 4, 2017](#) issue

### **In Review**



### **The Good Death**

An Exploration of Dying in America

By Ann Neumann

Beacon

There is no good death, I now know. It always hurts, both the dying and the left behind. But there is a good enough death.”

So concludes Ann Neumann in response to the central questions of her book: What is good about dying, and what are the forces that shape our individual experiences of death in the context of modern American medicine and culture? A journalist who is a visiting scholar at the Center for Religion and Media at New York University, Neumann roots her quest in a personal experience: her care for her father as he died from cancer. Neumann’s book joins several other fine, recent books on death and dying, including physician Atul Gawande’s *Being Mortal* and Oliver Sacks’s personal reflections on his dying in *Gratitude*. Compared to the philosophical and theological analysis of the ethics of death and dying by professional bioethicists, these books provide constructive experiential perspectives on dying through the voices of patients, doctors, and nurses.

Where Neumann’s book begins—personal, up-close experience and observation—remains its main strength throughout. After her father’s death she volunteered with a hospice program in New York City, an experience she recounts through narratives of an AIDS patient in a group home, an elderly Puerto Rican immigrant, and a well-educated, upper-class elderly woman. These personal stories give readers insight into the diversity of experiences people have at the end of life.

Interspersed with the individual stories is helpful background on the hospice movement and the evolution of bioethics since the advent of life-sustaining technologies such as ventilators and artificial means of nutrition and hydration. She discusses well-known cases, including the stories of Nancy Cruzan, Karen Quinlan, and Terry Schiavo. Readers without extensive background in the professional literature on death and dying will also find helpful references to influential thinkers and books which have shaped the conversation about end-of-life care.

In response to her own question about what is good about death, Neumann focuses a great deal of the book on opposing ends of the national discussion of autonomy in dying. One side of this discussion is represented by the legalization of physician-assisted suicide (also called “aid-in-dying”), which began in Oregon with legislation passed in 1997. Neumann provides an overview of the recent history of such legislation (now present in various forms in multiple states) and introduces the reader to significant figures and organizations, such as the Compassion and Choices

advocacy group.

On the other end of the discussion about autonomy and dying are the opponents of “aid-in-dying” measures, which include pro-life organizations and a vocal segment of the disability rights movement. Neumann highlights Christian pro-life advocacy groups with a particular focus on Roman Catholicism. She also talks with outspoken advocates from the disability community who think that arguments for physician-assisted suicide (for instance, that living in a state of dependence on others is an unbearable condition) further undermine the dignity of disabled persons.

A third perspective on the autonomy debate arises with end-of-life care in the context of prisons. For Neumann, prisons provocatively exemplify how policies, institutions, and professionals can constrain the autonomy of individuals, forces which she argues are also present in our mainstream health-care system, legal system, and religious traditions.

Neumann’s emphasis on the principle of autonomy provides an important reminder that the definition of a good dying experience is a deeply personal, individual process that demands the support and respect of the medical community and society. Given the significant role religious faith plays for many people in that meaning-making process, it is unfortunate that Neumann provides such a shallow, one-dimensional depiction of religion.

For example, her discussion of the Roman Catholic position on the withholding or removal of artificial nutrition and hydration focuses only on the extreme pro-life voices, ignoring the nuanced and diverse perspectives found among many Roman Catholic bioethicists and church leaders. Her bias leads to inaccurate claims, such as the equating of Catholic hospitals with prisons as places where “autonomy is suspended by institutions” and “where people are not free to choose what does or does not enter their body.”

Neumann treats every entity that offers normative ideas about death and dying (including hospice and the disability rights community) as a threat to autonomy. This approach ultimately hampers her goal of providing “breadth and depth” to our understanding of dying in America.