

Book Review

Title: *End-of-Life Issues and Persons With Disabilities*

Editors: Timothy H. Lillie and James L. Werth, Jr.

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Reviewer: Mark F. Romoser

This is a collection of scholarly articles originally published as a special series in the *Journal of Disability Policy Studies*. As such, it makes no claim to give a neutral presentation of the issues surrounding the end of life as it pertains to people with disabilities, particularly physician-assisted suicide (PAS). Rather, prominent opponents of PAS, such as Paul Longmore and Ron Amundson, professors at San Francisco State University and the University of Hawai'i at Hilo respectively contribute the bulk of the articles. Longmore analyzes the issue within the context of the larger disability rights movement (pp. 144-155), while Amundson, along with Hilo resident Gayle Taira, offers a more personal perspective (pp. 73-78).

The most frequent contributor from the pro-PAS position is Karen Hwang of Kessler Medical Rehabilitation and Research in New Jersey, who gets in some interesting points: "supporters of PAD [physician-assisted death, as opposed to "suicide"] assert that emphasizing vulnerability contradicts the goals of the independent-living movement by promoting the image of people with disabilities as a weak class incapable of full self-determination" (p. 20), and "a lot of us were left wondering why so much attention was being paid to the (Terri) Schiavo story when there are around 400,000 *thinking, feeling* citizens with disabilities under 65 languishing in nursing homes" (p. 183; emphasis hers).

Dr. Richard Radtke addresses an issue frequently mentioned by PAS proponents, that of unmanageable pain. Dr. Radtke describes his experience with trigeminal neuralgia, an excruciatingly painful condition that can accompany MS. For nearly a year, he was unable to eat solid food or even speak (p. 82). Yet, he emphatically rejects the notion that pain alone can cause life not to be worth living. He recalls a friend telling him, "If you can feel pain, you sure as hell can feel pleasure" (p. 82).

Other articles cover a broad spectrum of specific end-of-life issues ranging from dementia (pp. 124-134) to AIDS (pp. 113-123). There are discussions about withholding treatment and the emerging notion of "futile care" (pp. 39-50), and even a piece dealing with something called "chronic sorrow" (pp. 100-112). Of interest here is a first-person account from the caregiver's point of view, told by Marsha Saxton (pp. 84-93).

The book closes with two pieces about the last disability-related end-of-life case to capture the popular imagination, that of Terri Schiavo. Obviously, the Schiavo case does not involve PAS directly, since someone in a persistent vegetative state such as Schiavo's cannot give consent. Rather, the pieces focus respectively on the images of Schiavo and other people with disabilities portrayed during the extensive national media

coverage of the case (pp. 167-182), and on the relationship between right-to-life and disability rights advocates, who found themselves in agreement that Schiavo's feeding tube should not be removed, but on little else (pp. 183-184).

The link to the abortion debate in the Schiavo case tends to highlight the similarly shrill emotional tone of the debate over PAS. This collection offers a way to step back and examine the issue from a reasoned, scholarly perspective, something not often found when the subject is as emotionally charged as PAS.

At its steep price, this book is not for a general audience, but certainly for those with an abiding interest in the subject, and for libraries and other institutions wishing to build a collection of topical works in the disability field.

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