

[Robin's pitch letter]

7 January 2013

Hi, Vera --

If Peggy Battin hadn't had a cold that November afternoon in 2008, she'd have gone bike riding with her husband Brooke Hopkins. Instead, she went to a lecture on campus at the University of Utah, where Battin is a philosophy professor specializing in the ethics of end-of-life care and physician-assisted dying. So she wasn't in City Creek Canyon when Hopkins had his collision, flew from his bike onto the mountain path, stopped breathing, turned gray, and was resuscitated by a passing jogger who happened to be a flight nurse. She wasn't there when the ambulance rushed him to University Hospital, where he stopped breathing once again in the ICU. By the time Battin saw her husband, tethered to all the invasive machinery she'd always thought might make life intolerable, many of the decisions about intervention had already been made, and Hopkins' DNR advance directive had already been serially ignored. The only decision for Battin was to deal with the outcome -- and, in the process, to re-think her entire career of advocating for the right to choose the timing of one's own death.

Battin had spent thirty years studying the ethics of euthanasia and assisted dying not only for the terminally ill, but for anyone whose life had become intolerable. In books such as *The Least Worst Death* and *Ending Death: Ethics and the Way We Die*, she'd presented the case for maintaining autonomy up to the last moments of life. And now she was confronting these questions -- which had previously been remote and hypothetical -- in the most painfully personal way possible.

Four years later, Hopkins, 70, is still alive, still paralyzed, still dependent on a ventilator. As of last month, he's nourished via a feeding tube -- an intervention that both he and his wife might once have considered a line in the sand. Yet as much as Hopkins might resemble Battin's hypothetical candidate for "rational suicide," the one she pictured as she wrote her books and testified in favor of death-with-dignity legislation, the last four years have taught her that this is a more complex subject than even she had imagined.

"The irony of this situation is not lost on me," Battin, 72, told me when we spoke by phone recently. She had settled herself into a chair in the sunroom of her home in Salt Lake City, where Hopkins was still recovering from his second hospitalization in six months, this one for another bout of drug-resistant pneumonia caused by aspirating some food (hence the feeding tube). With every emergency illness, Hopkins submits to more and more invasive treatments -- something Battin encourages, even though she knows her husband looks to an outside observer like someone with such a low quality of life that death would be preferable. That's because, when things are going relatively well, Hopkins thinks

of this final stage, this near-total paralysis, as a kind of adventure, and occasionally experiences a thought or sensation that he considers "luminous."

When things are going badly, though -- during one of the hospitalizations to cure one or another of the raging infections that begin in his lungs or scrotum, or during one desperate stretch in 2012 when sensation returned to his limbs and back in the form of unrelenting, intractable pain -- Hopkins fantasizes about death. Self-starvation, maybe, or removing himself from the ventilator (he's trying to learn to breathe unassisted, but usually manages no more than a few hours at a stretch). And Battin, a fierce proponent of assisted dying when life becomes intolerable, has to struggle with how to help the man she desperately loves and desperately wants to keep alive while abiding by her own principles to respect his right to choose how and when to die.

So they soldier on, with a staff of 12 rotating through the household to keep Hopkins' inert body functioning. Battin still carries a full teaching load, and even Hopkins, at the time of his accident a newly-retired professor of English, continues to teach adult-ed classes in his home, lecturing about the works of Shakespeare, Chaucer, Homer, and Dante. And Battin wonders whether she can bear re-reading her earlier work about end-of-life decision-making, or whether she'd just want to tear up everything she ever wrote.

"I keep thinking about [Tolstoy's character] Ivan Ilych," wrote Battin, who has an MFA in fiction writing in addition to her PhD, shortly after the accident, "confronting the gnawing realization that he had what we would now identify as a fatal cancer, asking 'What if my whole life has been wrong?'"

I'd like to tell the story of Peggy Battin and Brooke Hopkins as a way to investigate the complex question of euthanasia -- Battin's "least worst death" -- for *The New York Times Magazine*.

Best,
Robin