As They Lay Dying

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Katy Butler, *Knocking On Heaven's Door: The Path to a Better Way of Death*

NEW YORK: SCRIBNER, 2013. 336 PAGES, CLOTH, $25.00.

Meghan O'Rourke, *The Long Goodbye: A Memoir*

NEW YORK: RIVERHEAD, 2011; PAPER REPRINT, 2012. 320 PAGES, PAPER, $16.00.

Douglas Bauer, *What Happens Next: Matters of Life and Death*

IOWA CITY: UNIVERSITY OF IOWA PRESS, 2013. 168 PAGES, PAPER, $17.00.

Six weeks after his father died of a brain tumor, Philip Roth dreamt that the old man returned from the dead, furious that his son had buried him in a shroud. "I should have been dressed in a suit," the elder Roth scolded. "You did the wrong thing." When he awoke, Roth understood that his dream-father had been angered not by his son's choice of burial clothes, but by his writing of *Patrimony* (1991), the memoir in which Roth recounts the dream: "In the morning I realized that he had been alluding to this book which, in the unseemliness of my profession, I had been writing all through his illness and dying."

Roth is not the only writer who has taken notes at a parent's deathbed. Simone De Beauvoir's *A Very Easy Death* (1985) is a classic memoir about a parent dying, and the last several years have seen a boom in this sub-sub-genre: Blake Morison's *And When Did You Last See Your Father?* (1998),

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Donald Antrim's *The Afterlife* (2007), Robin Romm's *The Mercy Papers* (2007), and Meghan O'Rourke's *The Long Goodbye* (2011) are but a few. This past year, two excellent books joined the growing list: Katy Butler's *Knocking On Heaven's Door: The Path to a Better Way of Death* and Douglas Bauer's *What Happens Next: Matters of Life and Death*.

When my own parents died—my father in 2004 and my mother in 2009—I felt a strong desire to write about them. Many needs fueled this desire: a need to make sense of my parents' lives and of my relationship with them; a need to expiate the tremendous guilt I felt in being unable to prevent their demise (the fact that I am a doctor compounded this guilt); and a need to face, on the page anyway, the inescapable message of my parents' declines and deaths, that my turn is next.

Surely people have always felt such emotions when losing their parents. So how to explain the rising numbers of memoirs about that experience just now?

Part of the explanation is the popularity of memoir generally, but the popularity of this particular kind of memoir reflects a demographic reality: people are living longer and dying more slowly than ever. Baby boomers, and the generations following them, are more likely to spend a prolonged period of time with dying, elderly parents than their ancestors did. During these months—or years—family conflicts intensify or resolve, long-hidden secrets are revealed, and parents and their adult children who have lived apart for decades may find themselves in newly intimate proximity. In other words, dying parents are good material for memoir. Or, to put it in less "unseemly" terms (to borrow from Roth), dying parents offer a memoirist an opportunity to tell a story that is both intensely personal and broadly resonant—i.e., what all memoirists hope to do.

Katy Butler's *Knocking on Heaven's Door* is both personal and resonant. Her account of the eight agonizing years between her father's stroke and his death is an ambitious hybrid of memoir, history, and self-help. She uses her family's unique circumstances as a springboard for a thoughtful discussion of why we subject people at the end of their lives to painful, expensive, and often futile medical treatments—and how we might avoid doing so.

In 2001, Butler's parents, Jeffrey and Valerie, seemed to be enjoying the perfect retirement. In their 70s they were both in excellent health and their home in Middletown, Connecticut, allowed easy access to the cultural and

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intellectual attractions of Wesleyan University, where Jeff had taught history. Their daughter Katy, a freelance journalist in her 50s then, lived in California. Her relationship with her parents had been conflicted at times and she was, as she writes, "comfortable loving [them] from a distance."

On November 13 of that year, Jeff suffered a stroke, the devastating effects of which his daughter describes this way: "The man who taught me how to take a bath would never again take one on his own. The man who taught me to revel in words and stories could not speak."

Butler's self-reference is not to be mistaken for self-pity or self-indulgence. She is making the point, as she does throughout the book, that illness affects not only the ill but a whole family. In the aftermath of her father's stroke, Butler became a member of the "roll-aboard generation," traveling back and forth across the country—her brothers absented themselves—to help her exhausted and often irascible mother care for her father. As she did, though, she was never quite certain of her proper role:

> A generation or two earlier, my path would have been clearly marked. I'd have moved into my parents' house, eaten the food at their table, and taken up the ancient burden of unpaid female altruism.

A year after Jeffrey Butler's stroke, his cardiologist recommended that a pacemaker be implanted in his chest to regulate a slow heart rate. The Butlers weren't sure that this intervention was a good idea for Jeffrey, who was, at that point, quite debilitated. But the cardiologist expressed no doubt about the device's benefit, so they agreed to it. "They had been," Butler writes of her parents, "by and large, in control of their lives and they did not expect to lose control of their deaths." And yet, lose control they did. For seven years, the pacemaker "kept [Jeffrey's] heart going while doing nothing to prevent his slide into dementia, incontinence, near-muteness, misery, and helplessness." A year before Jeffrey died, Valerie asked her daughter's assistance in having the pacemaker turned off, in effect euthanizing Jeffrey. Katy Butler agonized over making this request, which, it turned out, no doctor would honor.

Knocking on Heaven's Door is a rich and detailed portrait of one family. We learn of Jeffrey and Valerie Butler's courtship in their native South Africa, Jeffrey's loss of an arm in World War II, Katy's happy childhood in Oxford,

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where her father finished his graduate studies, and her less happy adolescence and young adulthood in the United States. Katy's descriptions of relationships with her parents, her brothers, and the lover she leaves behind in California with each trip east are dynamic and multidimensional. At times, for example, her mother's nagging and criticism infuriate Butler so much that she severs contact with her; at other times, Butler sees fellow Buddhist Valerie as her "dharma sister." One senses that these conflicting feelings often coexist.

Unique as Butler's family's story is, she emphasizes that because we live in a society that hasn't figured out how to implement medical advances wisely, or how to allow people to die in a dignified way, many other families are having similar experiences. As Butler puts it,

> Every day across the country, family caregivers find themselves pondering a medical procedure that may save the life—or prevent the dying—of someone beloved and grown frail . . . This is not a burden often carried by earlier generations . . . We are in a labyrinth without a map.

At the end of *Knocking on Heaven's Door*, Butler offers "A Map Through the Labyrinth," practical advice on caring for elderly parents and making decisions about medical treatment at the end of life. She includes information about hospice and palliative care, dividing duties among siblings ("Don't let brothers off the hook"), and resisting a "never-say-die death in intensive care."

Butler also offers this piece of somewhat less-expected advice: write. During Jeffrey Butler's decline, Valerie kept a journal in which she recorded both her frustration with her husband and her shame at being frustrated. Jeffrey himself toiled over a brief autobiography of his wartime experiences. And Katy Butler exchanged "love letters" with her dying father:

> They were simple letters, as if written by a five-year-old girl. Knowing that his visual brain was less damaged than his language centers, I put drawings in the margins and within the text . . . I no longer had to worry about how he'd edit my work or what he'd say about my risky career. He wrote back more tenderly than he could speak. It was the laboring that counted for me, the fact that he'd spent an afternoon making something, a gift, for me.

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Knocking On Heaven's Door, too, is a gift to readers—especially those who have cared for or will care for dying parents (i.e., most of us). Butler offers a map through the labyrinth of medical decision-making but, more importantly, through the emotional wilderness that a child of any age enters when a parent is dying.

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Meghan O'Rourke was barely in her 30s when her mother died of colon cancer. In *The Long Goodbye*, her memoir about losing her mother, O'Rourke, like Butler, rails against the aggressive last-ditch therapies that make the end of life so miserable for patients and their families. "Hell, I thought bitterly," she writes, with the sharp intelligence evident throughout her book, "[is] technology in the presence of inevitable death." O'Rourke doesn't gloss over the endless rounds of chemo, the frequent CAT scans, and emergency room visits that marked the degradation of her vibrant mother into a helpless and pathetic creature. But O'Rourke's subject is not so much dying as its aftermath: grief. For her, grief is the labyrinth with no map.

Grief disorients O'Rourke for both general and personal reasons. Generally, she argues, our society's skittishness about grief makes it difficult for those in mourning to heal, or even to articulate their pain:

> Although we have become more open about everything from incest to sex addiction, grief remains strangely taboo. In our culture of display, the sadness of death is largely silent. . . . What does it mean to grieve when we have so few rituals for observing and externalizing loss?

More personally, O'Rourke's grief is complicated by the fact that, unlike Katy Butler, she was quite young when her mother died. While the reversal of roles—child caring for parent—is difficult at any age, it's especially challenging when the child is still emotionally dependent on the parent. Barbara Kelly O'Rourke died at 55. The memory of her as the fun, cool mom who worked as a popular administrator at her kids' school was still fresh in her daughter's mind when she was called upon to bathe and feed her. "Was I still her child?" O'Rourke wonders poignantly. In an emotional tailspin as her mother was dying, O'Rourke rushed into marriage, divorced eight months later, and had

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an ill-advised affair. In other words, she was a young woman who really needed her mother. O'Rourke writes: "I was irrevocably aware that The Person Who Loved Me The Most In The World was about to be dead." This is a sentiment shared by "orphans" of any age—a 60-year-old friend whose mother died recently asked me, with a sad smile, if I would "adopt" her—but one senses that O'Rourke's orphanhood isn't the kind in quotation marks.

Compounding her grief is the fact that O'Rourke suffers from anxiety, particularly about death. As a child, her mother comforted O'Rourke when she confided her fear. And unexpectedly and movingly, caring for her dying mother also helps assuage her anxiety. Thinking about how she and her brothers needed to help her mother up from the toilet, she writes:

> It was what she had done for us, back before we became private and civilized about our bodies. In some ways I liked it. A level of anxiety about the body had been stripped away, and we were left with the simple reality: Here it was.

Like Butler, O'Rourke writes (and reads—*Hamlet*, C. S. Lewis) to make sense of her pain. At five, she had been encouraged by her mother, who gave her a red corduroy-covered journal. O'Rourke now writes, as she puts it, to "find a metaphor" for her mother's death. But she seems less confident than Butler about the healing power of writing. At the end of *The Long Goodbye,* fifteen months after her mother's death, O'Rourke admits that while she has committed her grief to the page by writing her memoir, and does feel somewhat better for having done so, that grief lives on:

> What can I say? There's nothing "fixed" about my grief. I don't have the same sense that I'm sinking into the ground with every step I take. But there aren't any "conclusions" I can come to, other than personal ones. The irony is, my restored calm is itself the delusion. I'm more at peace because that old false sense of the continuity of life has returned.

For Douglas Bauer, the "continuity of life" appears, at first, to be no comfort. In his memoir, *What Happens Next?*, Bauer moves back and forth between his mother's death and the series of infirmities that signal his own aging. An answer to the question he poses in the title of the book seems clear: *your parent dies—and then you do*.

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What could have been a depressing theme becomes, in Bauer's skilled hands, a lyrical reverie. *What Happens Next?* includes nine loosely linked essays that, as Bauer advises in his introduction, can be read individually but are best "read from start to finish, since it's organized to move along with a sense of the tale gathering and building."

The "tale" is really two tales: Bauer's mother's story and his own. In his early 60s, Bauer underwent cataract surgery. The operation was, like Bauer's stiff knee and the rapid heartbeat he'd noticed on occasion, nothing serious. But, he writes of these minor afflictions, "[i]t was as if they'd colluded in a devilish partnership to simultaneously launch the beginning mischief of age." Bauer woke from surgery in Boston to learn that his mother had just died, at 86, at a hospital in his native Iowa. He'd initially pictured himself hooked up to an IV at the very moment his mother had been similarly connected. But having learned from his brother that, in fact, his mother had no IV when she died, he writes:

> So I had been mistaken. We had not been joined, my mother and I. We'd not been twinned in the moment. We'd not been allied, except as a contrivance, through the unseemly [Roth's word again!] ease of my imagination. I would need to think on our history, hard and patiently, before it could be more than heavy-handed metaphor to say that I'd begun to see the world clearly on the day, in the hour, my mother died.

This combination of narrative humility and curiosity suffuses Bauer's lovely essays. Time and again he picks up possibly related phenomena and rather than forcing them to serve as metaphors for one another, invites us to explore them side by side. In "Tenacity," he interweaves images of his own faithfully beating heart on echocardiogram with his mother's several-hour crawl to the telephone after she fell and broke her hip, with the men at the shelter where Bauer volunteers: "They lived, these men, dog years of illness and abuse: one year aged them seven." In "What We Hunger For," memories of Bauer's long friendship with M. F. K. Fisher, whom he interviewed for *Playboy* as a young writer in 1971, inevitably bring up memories of his mother's kitchens. And Bauer conflates Fisher's death with his mother's and, by implication, his own. The book's final lines are:

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> Mary Frances and my mother. The two of them in desperate unison, become the same as they fought for life as life was leaving them; their gasping lungs; their frantic hearts; fortunate to grow old, disintegrate, and finally die.

Bauer doesn't specifically prescribe writing as balm for the confusion and pain of losing a parent, as Butler and O'Rourke do, but it is clear in *What Happens Next?* that he believes it is. How else to explain the gratitude with which he faces the prospect of his own eventual death at the end of the book? Or the hope he leads his readers gently to share: that one day we may be as "fortunate" to age and die as our parents did?

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