The New Old Age
Caring and Coping

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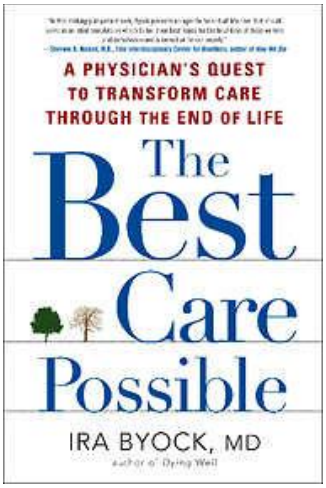
The Caregiver's Bookshelf: Dying by Degrees

By PAULA SPAN

Ira Byock has been writing books about the way Americans die since 1998, when he published "Dying Well." For most of that time, he has been appalled.



He still is. Dr. Byock, director of palliative medicine at the Dartmouth-Hitchcock Medical Center in Lebanon, N.H., pulls no punches in his new book, "The Best Care Possible: A Physician's Quest to Transform Care Through the End of Life." The American way of dying, he points out, involves too much suffering for both patients and families, and routinized medical response with not enough individualized care. It means not enough listening, not enough support for families, way too much expense. "A national disgrace," the author calls it in his introduction.

That we still aren't dying well has become a familiar refrain among those who talk and write about end-of-life care, here and elsewhere. What makes Dr. Byock's book particularly valuable is the chance to eavesdrop on the doctors we're often quick to blame. He tells what it's like on the other end of the stethoscope.

Physicians who comment here sometimes argue that they're more than willing to stop futile treatments, to refer patients with advanced disease to hospice care so that they can die gently at home. It's often families, they report, who angrily demand that patients remain in intensive care units, that doctors try one more procedure and then another, as though yielding to death were a moral failing.

Dr. Byock's narratives point to several such examples. He describes a meeting with family members of a beloved matriarch who's entering her fourth nonresponsive week on a ventilator in the I.C.U. He and the other doctors who've gathered in the room, all involved in caring for this 69-year-old with multiple health problems, see a bleak prognosis.

As he sensitively begins to discuss decisions with her children and their spouses, he can feel consensus building that although she has no advance directives (like most other Americans), this woman would not want to live this way.

Then her niece objects: “It isn’t right just to let her die. Only God can take a life.” Dr. Byock, accustomed to such conversations, feels the atmosphere shift as “people gathered their shoulders to their necks and looked down.” Having met the family only recently, he feels that pushing for a different decision would cause anger and resistance.

So the patient spends another week in the I.C.U. She undergoes a tracheotomy to help her breathe, has a feeding tube inserted into her stomach to provide nutrition and requires emergency neurosurgery to drain pressure inside her brain. The account is as potent an advertisement for advance directives — at least for those who’d prefer to avoid such a chain of events — as any copywriter could concoct.

Dr. Byock devotes a couple of chapters to the changes he would like to see happen. Personally, though, I was most appreciative of his front-line insights into the way medicine operates at the end of life. To be invited to sit in on his lecture about palliative care to third-year medical students, to see how good end-of-life care can be — that provides perspective it’s hard to find elsewhere.

I’m unhappy about the use of composite patients in some of these detailed portraits. If families refuse to allow publication of their names or details of their cases, the doctor has to honor their wishes. But to put Patient A’s words in Patient B’s mouth, or to describe a teenager’s bedroom that actually belonged to someone else — well, the word journalists use for such techniques is “fiction.” I wish Dr. Byock had resisted the temptation.

Otherwise, “The Best Care Possible” takes you into conference rooms and hospital rooms you cannot ordinarily penetrate, where conversations take place that are normally off limits to outsiders. They’re important to hear.