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Well-being in Dying — Preserving Human Potential Through the End of Life

When dying people are cared for in ways that meet their basic needs and honor their worth, the waning phase of life contains surprising opportunities for wellbeing

By [Ira Byock, MD](#), physician, author, patient advocate. Founder, Institute for Human Caring at Providence St. Joseph Health



The idea that someone might be “well” as they are dying may seem hard to believe. Let me suggest that’s because the care dying people receive has been so bad for so long and caused with so much unnecessary distress that few of us can think of anyone who died well. Collectively, our expectations are way too low.

I’ve been focused on improving care for seriously ill and dying people since the late 1970s. It wasn’t what I intended to do when I applied to medical school, but early on I realized that’s where the need was greatest. After all these years, it’s a crying shame to still witness sick people subjected to excessive, nonbeneficial treatments, lapses in medical competence and ungodly bills imposed by a dysfunctional healthcare system. We all should be furious.

We’d be angrier still if we realized what we’ve been missing. Because, while bad care can rob incurably ill people of any life worth living, the converse is also true. With excellent medical attention and sufficient social support, more people than you might suspect are able to experience a sense of wellbeing as they approach the end of life. Witnessing people who are *well* as they are dying is what hooks many of us who work in hospice and palliative care to careers in this field.

What do the words health and wellbeing really mean? Sigmund Freud was once asked to define mental health. As I heard the story, he was walking at the time and tossed off the answer: the ability to love and to work. Not bad. It holds up to a lot of pondering. A person doesn’t need to be happy to be healthy. On any given day people living in extreme poverty or surrounded by gang violence or dealing with the common stresses of unpaid medical bills, a job they hate, or divorce may feel miserable, yet remain fundamentally healthy.

Wellbeing is a step further than mental health. An adult who is able to work and love may qualify as psychologically and emotionally healthy, but for a person to be well entails a capacity for joy – mostly evident in an ability to laugh. There’s no doubt that extreme hardships can deprive even healthy people of any chance of feeling well. However, human beings are resourceful and resilient. Many of us find ways to adapt and, sometimes, even grow through difficult circumstances. Those unwanted circumstances may include incurable conditions and knowing that you are facing the end of your life.

Freud’s definition requires adjustments if we are to contemplate mental health in the context of advanced illness. Naturally, the normal frailties of being ill or old eventually make work, in the usual sense, impossible and simply irrelevant. Being healthy during the final months, weeks and days of life continues to turn on an ability to love and to *feel loved*.

Perhaps in this waning phase of life the relevant work people have to do revolves around important developmental tasks that include completing their affairs and personal relationships, loving others and feeling loved. And wellbeing during incurable illness? From what I've observed, being joyful and, at least occasionally, able to giggle or smile are reliable markers of wellbeing.

My father, Sy Byock, taught me about being *well* while dying. He didn't lecture me. He simply lived with the same authenticity, honesty, and integrity that he had all through his life. Dad hated that he was ill and the thought of dying. He loved life and all of us. But as he might say, "it is what it is." Dad's dying was hard. He felt lousy a lot of the time. Knowing that time was limited forced him to sell the business he'd built from scratch for less than it was worth to a competitor who knew Dad was ill and that he could drive a hard bargain. Dad put his legal and financial affairs in order. He and I had not had a perfect father-son relationship, so we took the opportunity to say things that fathers and sons rarely do – the Please forgive me's and I forgive you's. I told him how much I loved him and how proud I was to be his son. The months during which Dad was ill and dying were awful. But in some meaningful ways, they were also wonderful.

I have a photo of Dad a few months before he died. He is holding and making eye contact with Lila, my first daughter; his granddaughter. They are both ecstatic! His eyes radiate joy.

I've seen this degree of joy in the eyes of dying people or heard it in their laughter. When it occurs, it's almost always in the midst families, often while holding or playing with babies or young children, sometimes beloved pets.

As a young doctor I was appalled by the inattention and incompetence suffered by dying people. It seemed to be not just a failure of medical care, but an issue of basic human rights. When did they stop mattering? But I've never lost sight of the human potential that lies (mostly) hidden within the experiences of illness and dying.

When people are competently and tenderly cared for, many can feel a sense of peace – well within themselves and with others – as they leave this life. Preserving this opportunity is the fullest expression of community. Depriving people of the opportunity to die well seems the final social injustice.

So, let's not lose our outrage or surrender our joy.

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Dr. Byock is also active emeritus professor of medicine and community & family medicine at the Geisel School of Medicine at Dartmouth. He served as director of palliative medicine at Dartmouth-Hitchcock Medical Center in Lebanon, N.H., from 2003 through July 2013.

Dr. Byock has been involved in hospice and palliative care since 1978. His research has contributed to conceptual frameworks for the *lived experience* of illness that encompasses a continuum from suffering to wellbeing; related measures for subjective quality of life during illness; and effective life-completion counseling methods. From 1996 to 2006 he directed *Promoting Excellence in End-of-Life Care*, a national Robert Wood Johnson Foundation program that developed prototypes for concurrent palliative care of people with life-threatening conditions. He is a past president of the Academy of Hospice and Palliative Medicine.

Byock's first book, *Dying Well*, (1997) has become a standard in the field of hospice and palliative care. *The Four Things That Matter Most*, (2004) is used as a counseling tool widely by palliative care and hospice programs, as well as within pastoral care. *The Best Care Possible* (2012) tackles the crisis that surrounds serious illness and dying in America and the transformation that is possible.

Dr. Byock has been a featured guest on national television and radio programs, including CBS' *60 Minutes* (on three separate occasions), *PBS News Hour*, *Fox and Friends*, and NPR's *All Things Considered*, *Talk of the Nation*, and *On Being*.

More information is available at IraByock.org and InstituteForHumanCaring.org.

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