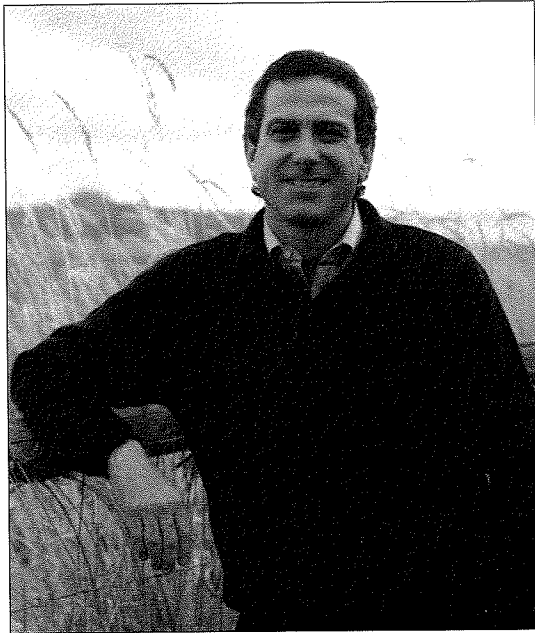


# An Interview with Ira Byock



*Ira Byock, MD, is president of the Academy of Hospice and Palliative Medicine, author of the book, Dying Well: Prospects for Growth at the End of Life, and national director of the Robert Wood Johnson Foundation's national program office, Promoting Excellence in End of Life Care, in Missoula, Montana. The Missoula office is supporting projects that promote excellence in end-of-life care. Recently he met with the Bioethics*

*Forum editor and shared his thoughts on his work, on palliative care, and on his hopes for the future of how people die in America.*

**Bioethics Forum:** Palliative care is a concept coming into its own, certainly, but is not yet a household word, even in some medical settings. Would you define it for our readers?

**Byock:** I usually fall back on the more formal definition, that offered by the World Health Organization. Palliative care is the care for the person and the family who are encountering life-limiting illness. It's care that is not directed toward life prolongation or cure but toward the quality of life of that person and family. It's an interdisciplinary team approach to care that focuses on patient and family as the unit of care.

Some of its precepts include ethical decision making that honors preferences of the person and the family; a strong emphasis on relief of physical distress; acknowledgment that dying is a part of living, and that in addition to the capacity for suffering, the person has the opportunity to do important things related to life closure and completion, and that human life has more than physical, emotional and even social dimensions, that it also has dimensions of meaning, spirituality, transcendence. It is caring for the whole person in the dimension of their family when cure is not possible.

**BF:** Clearly from both your definition and your work, you believe family is integral to palliative care. What do you do when the wishes of patient and the family don't come together?

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**Byock:** Struggle. It's hard, but you try to work with the patient and family to reach some plan that meets their preferences and values. When the patient is conscious and alert and has cognizant ability, their preferences obviously have precedence over those of the family, but to say that we apply a formula would not be accurate. Real compassion is well described by the old French from which the words "to suffer with" come. And really, at our best, that's what we do. Seeing the patient as a fellow on a journey that neither of us would chose is to invite true compassion.

**BF:** A psychospiritual component is often mentioned as being integral to true palliative care. Would you explain the connection?

**Byock:** Psychospiritual and psychosocial elements are dimensions of quality of life. And quality of life is integral to palliative care. If you look at the definition of palliative care we've talked about today and the National Hospice Organization's preamble to their standards' document, you see the emphasis on enhancing the quality of life at the end of life.

**BF:** For many people, palliative care means pain management.

**Byock:** It's not. We certainly have to reduce pain. But that is not the same as palliative care. Hospitals and home care agencies, for example, tell me they are 'doing palliative care' because they're working hard on communications and reducing pain. Nope. That's great, and needs to be done, but it's not palliative care; it's just good, competent medical care. Palliative care is seeing the person and family as the unit of care. It's acknowledging that dying is a multifaceted experience that we need to respond to with an interdisciplinary approach. Palliative care is acknowledging that dying is a part of living, that it has medical problems connected to it but those medical problems do not define the experiences.

**BF:** Is it possible to do this, to have true palliative care in hospitals?

**Byock:** Yes, it's possible. The definition of palliative care doesn't say where

it has to be. It's harder in hospitals because the culture of hospitals these days makes it hard to focus on the personal experience of patient and family, makes it harder to improve their quality of life. The medical institutional culture must focus on medical problems. People come to doctors with problems. Everything we do in adult medicine is focused on problems. In fact, some believe that if you can't chart it in a problem list — objective/subjective assessment and plan — then you shouldn't be doing it. That's a fine approach. It has organized medicine, resources, and energies dramatically for the last twenty years. But to see it solely through the lens of a problem-based model misperceives the experience of the person dying.

Dying is personal, and so much more than a set of medical problems to be solved. And it's much easier to focus on the personal when a person is in her own home; but it is possible to do this in hospitals.

As director of the Robert Wood Johnson Foundation's national program office Promoting Excellence in End-of-Life Care, we've emphasized that it is comprehensive end-of-life care that we are interested in supporting. We're looking for innovative models of palliative care that have prevented the provision of hospice care. Hospice care, for example, is difficult to provide in a hospital setting. It is somewhat less problematic, but still difficult, to administer in nursing homes. It's difficult in prisons, isolated rural areas, poor urban areas. But it is possible. And that is why the Robert Wood Johnson Foundation set up this program — to see those barriers as opportunities for innovation.

**BF:** Some refer to palliative care as "nice ... but is it medicine?"

**Byock:** Yes, I've had people challenge me with that. Well, yes, palliative care is medicine. It's just not adult internal medicine. What we do in the best practices of hospice care is really a lot more like what we do for newborns, infants, and toddlers. For infants and young children, society offers more than a biomedical approach. The therapeutic schema in pediatrics is to treat physical problems, developmental problems, and other problems we know of, to guide families through them, and to actively promote opportunities for the child and family to grow together. This is closely analogous to hospice care at its best.

Hospice acknowledges that people warrant our medical services during this time of life, not simply because of the problems they may be having, but because this is a critical time in human life that the patient — in their family and with their family — is living through. Internal medicine these days is almost solely problem based. If you don't have a problem, you don't get intervention. Hospice has shown that a more comprehensive approach is effective, even cost effective. Hopefully

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emerging systems of hospitals, nursing homes, and long-term care facilities will look more like this early childhood approach to medical treatment — the treat, prevent, promote grid — than the problem-based approach.

**BF:** Palliative care — hospice care, in particular — includes a huge number of services to the dying patient. Is there any chance that it, as has happened in curative medicine, will become too aggressive?

**Byock:** First of all, I like the word *intensive* better than aggressive. Intensive care can take place with other goals than those of intensive care units. And yes, there are a lot of resources that the palliative care team should have available. But they should be used only as the patient desires them and needs them. Our agency, for one, has been accused of having an agenda for having people die the way we hospice people think they should die. That's not true, but we do need to offer many resources. The current culture has its own agenda for dying people: having as few palliative care resources as possible. Such a culture doesn't acknowledge that dying is a part of living and that it offers opportunities for growth, for relationship completion, for life closure.

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The current culture imposes its own *de facto* impoverished model. I would like to offer that human life is fuller and more interesting. The care that we offer to people in their dying should reflect the acknowledgment of the fullness of human life, the potential for suffering, but also the potential for growth, even as we die.

**BF:** How do you look upon patients who don't want to have anything to do with what you have to offer, who simply want to close the door and die?

**Byock:** Sometimes, when you see things you could do and patients and families don't buy into it, there's frustration. But it's no more pronounced in hospice than elsewhere. The same would be true of a surgeon who knows she could help a patient. There's an *angst* in those situations because the desire to do more often comes from very good motives.

**BF:** Dying is a deeply personal time in one's life. The boundaries between what is personal and private and what is professional and therapeutic can become blurred. Would you comment on that?

**Byock:** The predominant culture agrees with that statement. And yet our medical culture directly impacts your personal experience, by keeping you in an institution, for example. And sometimes they'll take care of your physical needs and not your pain, and then you don't have a personal experience because it is captured by pain. Your fear of bills or the burden you might be to others destroys your ability to take care of the personal. I agree that we have to be careful not to impose our agenda on anyone, but

in working with people and in understanding their fears, it seems only responsible that we let people know what is available. It is absolutely their choice whether they want to use it or not. I ask people simple questions, like, "What matters most to you now?" and "If you were to die suddenly, are there things that would be left undone?" If they don't want to talk about it, I say, okay, I'll see them tomorrow. What I do is present the opportunity. Each person chooses for herself or himself; the individual's freedom is always preserved.

**BF:** Your book is called *Dying Well*, words I suspect you chose carefully. Would you explain why you chose this particular phrase?

**Byock:** Although many people today are talking about a "good death," I think that phrase blurs an important distinction between *death* — and *dying*. This even happens in medical journals. Death signifies a lifeless state, a state beyond life. But dying is a part of living. In choosing words to convey what success might look like in this time of human experience, I think we convey something important. *Dying well*, for me, conveys the sense of quality that people have taught me is possible in this time of living. Really the phrase "dying well" can be understood in two ways. "Well" can be an adverb for the quality of person's experience of dying. Or it can be an adjective describing the person who is dying.

It is time for us to acknowledge that a person need not be pathologic to be dying. If you think about some of the most emotionally robust people you know, consider that they, too, must die. Must they be considered ill *as a person*, simply because they are dying? No. As the generation of baby boomers challenged pathology and disease in childbirth, we need to explore notions of wellness even as we die. My experience is that people not only can be well, but they can become more whole, more integrated as they complete their lives. They can gain a better sense of themselves and their connections to others even as they are dying. That's what people have taught me over the years.

**BF:** You've written about the *responsibilities* of the dying, an uncommon concept. Please explain.

**Byock:** People are communal animals. In this country, we've confused Jeffersonian democracy and the notion of individuality that is so important in the context of social and legal rights, with the nature of what it means to be human. I applaud notions of individuality and democratic systems, but human beings are fundamentally social creatures and our connections to one another are profound. Often we think about responsibility only in terms of the responsibility we have toward people who are weaker than we are. Mainly that is true. But I believe that the social contract is that we all help each other, weak and strong alike. We are in

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relationships and these carry responsibilities. As we become progressively ill, our ability to respond often diminishes. But we retain a responsibility, even then, to accept care. I think the dying person has a responsibility, if possible, to participate in life/relationship completion and to tell his or her story so others can learn from it. If a person is fully capable and rejects care, through suicide, for example, the social contract has been abrogated. Society has an obligation to offer care. I would submit that at times of illness and dependency, we have a responsibility to accept it. In choosing not to take that responsibility, a person ends the social contract. Insistent demands for help in suicide represents a clear statement from the person that medical and human care has nothing left to offer. From my perspective, physician-assisted suicide is not an extension of care; it is the antithesis of care. To posit that people ought to receive help from society in preemptively ending their life, changes the very nature of the social contract.

**BF:** In many ways, we've lost a sense of community. In our current environment, one in which we sometimes don't even accept responsibility for infants and children, how can we expect success at the other end of life?

**Byock:** We simply have to. The value in caring for families and friends, of course, but even for strangers among us, is a primal, social value. To the extent we don't do it, we erode the quality of our lives.

One of the social forces that acts as a barrier against this kind of change in care is cost. But enlightened end-of-life care need not cost more than the hospital- nursing home-based system of care that doesn't serve the preferences of people very well. If we make wise policy choices now, in the future, as a society, we can have our cake and eat it, too. We should settle for nothing less. We need all sorts of changes to accomplish this new system of care: changes in policy, curriculum standards, legislative changes.

We need all of that but we can't wait for courts, congress, and state legislatures to get started. In the crisis that surrounds care for people in their dying in America today, we need everyone's help. We must insist on excellent medical care that addresses the preferences and physical distress of people as they die, but frankly, care for the dying is too important to leave to the experts. Each of us needs to take back responsibility to see that our friends, our family, our neighbors, and even strangers are cared for in ways that insure relative comfort, but also that honor and even celebrate the person in her or his dying. We need to insist that people are treated in ways that allow them not only to feel physically comfortable, but to feel wanted, worthy, and dignified in their terminal illness and social frailty. We cannot afford in this country to accept anything less.