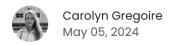
This palliative care doctor says dying can be a "rich time of life"

Even if you're on your deathbed, it's not too late to change and grow.









Hello, Mortal

SUNDAY

What does dying well mean to you?

For most people, it's about having a **good death**—one with minimal pain, relative physical comfort, and as much love, care and support as possible.

But for <u>leading palliative care doctor Ira Byock, MD</u>, there's another way to think about dying well that is deeper and richer, and even a touch provocative. By this definition, "well" describes not the dying process itself, but the internal state of the person who is dying.



Dr. Ira Byock

"Can the person be well within themselves, with the world, with the people they love, with their God or the universe or nature, as they are leaving this life?" asks Byock. "For me, that's the highest therapeutic goal I could have. My fondest wish is for the people I'm caring for to, in some way, experience a sense of well-being."

In a culture where death is denied and medicalized, dying well might sound like an oxymoron. But through decades of clinical experience with dying people, Byock has discovered that it is not only a real possibility but a fairly common occurrence. With excellent medical care and compassionate support, he says, many—if not most—people can die with a sense of peace and well-being.

Working with people in the final days, weeks and months of their lives, Byock has witnessed the remarkable healing, reconciliation and personal growth that can happen at the very end of life, both for the person who is dying and their loved ones. In his book *The Four Things That Matter Most*, he shares insights from the threshold of death that can help us to heal, grow and love more fully at any stage of life. The big takeaway? Don't wait to say the things you need to say.

We spoke with Byock from his home in Montana about breaking down the barriers to dying well, what death can teach us about how to live fully, and the importance of leaving nothing left unsaid.

This idea of "dying well" is at the heart of your work as a palliative care doctor, hospice advocate, and author. But you're not just talking about having what we might think of as a "good death." It's also the idea that people can experience true well-being as they are dying. What does it look like to be well while dying, and why is it so difficult?

It's hard because biology makes it hard, right? Dying is a hard process. We're animals and the biology of disease causes physical suffering and distress, and obviously it causes emotional distress because it sucks to feel badly. Think about when you have the flu or if you've had COVID: it's awful to feel physically bad.

Some people in my field who I have this conversation with look at me like, Well, everybody I see is suffering. I'm just trying to keep them from suffering. What are you talking about? But in fact, we know it's possible [to be well in the dying process]. If you observe other people in the course of your clinical work—or you read biographies of people who were obviously well in the last months, weeks or days of life—it clearly expresses a sense of well-being.

We know it's part of the human endowment, or part of human potential, but the biology makes it hard.

These days a big barrier to dying well is also that our health system is terrible at this. Even with hospice and palliative care, mainstream medicine doesn't do this well. There's a kind of phobia within American healthcare and Western medicine in general that sees death as a failure.

Part of what we do in hospice and palliative care is we've become very sophisticated at alleviating people's symptoms: their pain, their breathlessness, their sleeping problems, their GI problems. We're not perfect at it, and many people can't become completely comfortable, but we're better at it than I think the general public understands.

We tend to think more is better, so you end up pushing it, helping people live longer. They want to live longer, of course, and their families want them to live longer. So you keep bringing ever more intensive treatments to preserve life. But ultimately, that's like pushing someone against an immovable wall because death is the *force majeure*, and it will have its way.

American medicine for all of its prowess—and it does some things remarkably well, miraculously well—tends to approach people's health in a very transactional way. You come to doctors with problems. We analyze your problem and we come up with a plan. But as individuals, as patients, we experience health and illness and certainly dying very personally. So the way to respond is not as a transactional healthcare system, but as a *relational* health care system, understanding people as whole persons. Not skimping on the prowess of disease treatment, but also attending to people's symptoms, their comfort, their quality of life, their fears, their hopes, their concerns about the people they love and the people who love them. All of that can be done, but in general, we do a lousy job of it.

What would it take to develop a relationship healthcare system that treats patients as whole people? Do you think there needs to be more collaboration between different disciplines to address all the different layers of what's happening in the dying process?

Yes. And, every clinician, every doctor, every nurse, every social worker would benefit from extra training in seeing people as whole persons rather than a list of problems that we need to analyze and solve.

It seems trivial or silly to be saying this, but it would make a huge difference if we reframed the focus of medicine as a system of caring for whole persons rather than as a system for treating diseases.

And I imagine that would require us to stop pathologizing death.

Yes, I agree with what you just said—but I would distinguish that *dying* needs to be seen as a normal process. In a sense, death is beyond life. I don't know anything about death. Never been there. I don't know anybody who's ever convinced me that they know a lot about what's happening in death.

Dying is a part of living. It's inherently hard. It's unwanted, but it is not without its own human potential value. It is potentially a rich time of life that does not always preclude a sense of well-being.

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Can you say more about that? What is the value and potential that is present at the end of life, based on your observations?

My worldview is that there are inherent stages of human development from neonatal development to early childhood development to adolescent development to adult development. And mostly, development is sparked by crises. There are developmental crises when the toddler starts to stand or when the child goes to kindergarten. When the adolescent or young adult leaves home and gets married. There are midlife crises when somebody loses their job or maybe the spouse leaves the person. All kinds of things.

Most of us negotiate those crises in a way that enables us to grow well. Who we are during the crisis is different than who we were before. The world sees us differently. We see the world somewhat differently. And we have to change or we will suffer. Stay with me here. At any chronological age of life, if somebody develops an incurable cancer or has a massive heart attack and now has substantial congestive heart failure or develops ALS, their illness and the very real prospect of dying becomes a developmental crisis.

Who they are now is different from who they were before they started having symptoms and were diagnosed with this illness. Everybody around them sees them differently. Their expectations are different. There's a lot of suffering if you continue to have the same expectations you've had about your job, your career, your relationships with those you love and those you know socially. There's a lot of pain.

The way through that is to live as fully as possible with the reality of how this sickness impacts and changes your life. But time and again, I have seen people change in ways that I can best describe as growing through incorporating this new reality and adjusting their own expectations of life. You change plans and negotiate the developmental tasks of this difficult, unwanted, but normal stage of human life.

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What might that look like?

People say and do the things that they would feel would be left undone if, on any given day, they died suddenly. Which is hardly abstract if you have congestive heart failure and are having runs of VTAC or you have cancer and because of your treatment you have no white blood cells left and you could get septic at any given day, or you could have a stroke.

One of the things I talk about a lot in my book, The Four Things That Matter Most is, this is a good day to say the things that might be left unsaid between you and someone you love or once loved. Most of us in adulthood—and certainly those of us in middle age or beyond—have a history of some relationships with close friends or lovers or relatives who we've grown estranged from. Sometimes, standing in front of the monolith of mortality, the infractions and the anger that's divided us begins to look small in proportion to the life we've shared and the things that at one point attracted us to each other. It's about saying the things that would be left unsaid: the please forgive me's and I forgive you's and thank you's and I love you's and If we're not able to see each other again, good-bye.

We've talked before in this newsletter about the <u>importance of storytelling</u> at the end of life. It sounds like this is something you've observed as well. What other kinds of things tend to create a sense of well-being for the dying person?

There's also leaving a legacy for other people by passing on not only treasured objects, but treasured stories. Stories are far more valuable than the rings and wedding dresses and old saddles or whatever. You can't take any of it with you, but the stories are part of what makes us families and friends and communities.

One thing I've done with people for years is try to get them to record their stories.

Every time I've done that, we've created an heirloom for the family. My mother did this years ago, in the 1970s, with my maternal grandmother, interviewing her about emigrating from Russia as a 12-year-old girl. She talked about what her life in Russia was like, and about living in New York and New Jersey at the turn of the century.

Then, there are the things we do to honor and celebrate people—that's part of what we do to grow together as a human community. We have wakes and hold vigils and have celebrations of life—if possible, before the person dies. It's much more fun that way. But if not, after the person dies. This is part of how we care for ourselves and one another.

All of this has to do with cultivating and fostering a sense of well-being, sometimes even in the midst of the person feeling not good. The dying person doesn't feel great physically. They say, I feel kind of lousy, but emotionally, oh my God, this is one of the best days I could imagine.

You're describing this incredible healing and growth that can happen at the very end of life through this crisis and, it seems to me, almost a kind of initiation. Do you think that by contemplating death or having some practice around being aware of our mortality, we can experience this kind of growth earlier on? Can we have those wake-up calls and realizations sooner?

It is without question true that acknowledging our proximity to death at any given moment and any given day helps us to live more fully. That may seem paradoxical, but I found even in my personal life that being aware that when I get behind the wheel, I could have a fatal car accident keeps me very aware of the gifts of life every day, every moment.

It makes me ever more compelled to make sure my relationships are current. I don't hold grudges. I'll talk to people to ask for forgiveness when I've screwed up, which I continue to do. I'd like to think we all do from time to time.

I'm much more quick to apologize. The point is that when there's nothing critically important left unsaid or undone between you and those you love and care most about, there is a sense of celebration that creeps into our relationships and our lives. What I mean by celebration is not hats and confetti. I mean celebration as gratitude for the intrinsic value of this moment, of who we are together and the gift of life. That's what I mean. Celebration is: *Oh, isn't this great?*

When we begin to face death, we begin to live fully.

You must see a lot of fear and denial, and probably just trouble letting go in the people you work with who are dying. How do you work with that? What have you seen to support people when they're really struggling with the fact that they are dying?

As a physician, and usually practicing as a member of a clinical team, like a hospice or palliative care team, it starts by absolutely assuring someone that they will not be abandoned, that we are always available. We're always at the other end of a phone, just like that, if they need us.

We're assuring them that there's always something more we can do to alleviate their physical distress... There is no situation—and I rarely as a doctor say anything so absolute—but there really is no situation in which we cannot do something more to alleviate somebody's physical suffering.

In a personal counseling realm, I don't really talk about people needing to accept the fact that they're dying, but I can help them in very tangible ways to to feel more ready, that there are less things they have to do before they leave this life.

If a person has amorphous anxiety about I'm just not ready to die, I'll gently probe them, If you, God forbid, you were to die suddenly today—as any of us might—do you have a sense that there are important things that you would have left undone? Or that you would be letting somebody down? Those are things we can work on to get to a sense of at least feeling there's nothing critically important left undone.

If you had one last piece of advice to share before your own death, what would that

Life is a precious gift; it's simply a finite gift. The goal in life is not to live as long as possible, but to live as fully as possible.



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We should all drink deeply of the frankly miraculous gift that life is. Enjoy it. Approach life and your relationships with an open heart. Be forgiving toward yourself and others.

Celebrate each day. Sing loudly, dance in the rain.

That's the secret of life: to live as fully, as joyfully, as possible.

This interview has been lightly edited for length and clarity.