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Real Issues in End of Life Care

Announcer:
You're listening to ReachMD, the channel for medical professionals. Welcome to Inspire to Act, featuring international leaders in the field of medicine. Here is your host, Founding Chair, Department of Neurology, Brigham and Women's Hospital and Professor of Neurology at Harvard Medical School, Dr. Martin A. Samuels.

Dr. Martin Samuels:
End of life care is very much in the news these days. Public discussions about end of life care generally devolve into questions of physician assisted suicide or so-called death panels.

Perhaps the topic is so charged because there's really no alternative to dying. For us and our patients, like birth and taxes, end of life is inevitable. Joining us to discuss the real issues in end of life care, and what can we, as physicians, do to more compassionately provide for our patients, is the Director of Palliative Medicine at Dartmouth Hitchcock Medical Center in Lebanon New Hampshire, Author and professor at Dartmouth Medical School, Dr. Ira Byock.

Ira, thanks, very much for joining us today.

Dr. Ira Byock:
Well, it's a pleasure to be with you.

Dr. Martin Samuels:
Let me start, before we talk about the substance of the matter, a little bit about your career. I think a lot of people will be wondering how did you go from family medicine, I think you were trained in family medicine, to working in a hospice and taking care of dying patients?

Dr. Ira Byock:
It is quite a story. I thought I was going to be a rural family practitioner, then actually chose a very demanding residency program to train me in all sorts of things, including critical care, and some trauma and surgical things that I needed to do to practice independently in an isolated rural area. Along the way, however, I got very interested in seeing patients who are approaching the end of life and being surprised frankly, that when we were able to make people comfortable, physically not in distress, every once in a while, when I asked somebody, "how are you doing today?" the answer would be some version of "I'm well, Doctor, how are you?"

And I had no place to put that information. You know, the first few times I heard that Marty, I thought, 'well, it's the morphine. Sure they're feeling well.' Or, 'It's the steroids that they're on.' But I had to begin to realize that there was something more interesting happening here. That actually they were expressing a sense of wellbeing, and from a western perspective, it's very hard to understand how somebody could say that they feel well, when they fully know and acknowledge that they were in the process of dying.

So that got under my skin, frankly, and while I became involved in establishing a small hospice program way back in 1978 in a county hospital ins Fresno, California, in addition to practicing family practice and then going on and having a 14-plus year career in emergency medicine, getting board certified in emergency medicine, throughout all of this time, I continued to be involved in hospice work, and continued to sort of read and think about, and even do some research about this notion of wellness and a subjective experience of wellbeing when somebody is facing the end of life.

Dr. Martin Samuels:
That's extraordinary. I think a lot of people, don't you get depressed by dealing with people who are dying all the time? It doesn't sound like you do. What keeps you optimistic and looking forward in the face of dealing with death every day?

Dr. Ira Byock:
You know, I'm just here to serve. I try to bring all of my medical training and expertise to be of value to people during an inherently difficult time in human life. What I have in common with so many other specialties that deal with seriously ill patients, I didn't give them this injury or illness. I'm just here to be of value to them.

What I found though, is that people are just people, and you know, this time of life, although it is hard, unwanted in general, and without romanticizing it, I have found that this time of life has its own value. In addition to the risk of suffering that we all have as we face the end of life, there are things that reliably people say are important to them and they value. Time with other people. Time with the people they love. Making sure that they leave nothing left unsaid with people they love. A chance to review their lives and perhaps tell their stories. A chance to frankly, celebrate he gift of life and relationships, are really what matter to people most, when the stuff that fills our day planners and our palm pilot starts to fall away because of the disabilities associated with progressive illness.

So it's all about life and it's not nearly as depressing as people assume to be caring for people who are living with advanced illness.

Dr. Martin Samuels:
You've written about the four things that matter most, which are please forgive me, I forgive you, thank you, and I love you. How universal have you found those to be, Ira?

Dr. Ira Byock:
Pretty universal. You know, I approach people with the notion that it might be of value to them, and I kind of…my way of introducing this to people is to wonder with them, if it might not be of value, to at least have said four things to one another, before they're forced to say good-bye. Please forgive me and I forgive you, because it turns out there hasn't been a perfect relationship in the history of our planet. Even our most close and loving relationships tend to have some history of misunderstanding or hurt feelings or sometimes real transgressions, and clearly many people come to the end of life with fractured relationships that they have long assumed will never be healed, but suddenly, when one or the other person is forced to face to the fact that time is short. Sometimes the things that have divided us, even the transgressions and anger that have divided us, begin to look small in proportion to the bonds that are between us, the connections that we value.

So I wonder with them if it wouldn't be of value to say please forgive me. I forgive you. And then thank you and I love you is often an exercise in stating the obvious, but boy, I think there is no other place where saying the obvious has as much value. Why wait?

Not uncommonly, in fact it happened…last week, I was in the ICU family meeting room with a family. The mom of this family is seriously ill, not clear that she's going to survive, we're not sure how much she's understanding, and I wondered aloud with the group after we got done with some of the information about her condition, the treatments, her prognosis, would it have value for you to say please forgive me, and I forgive you, thank you, and I love you to one another? As is commonly the case these days, one of the adult daughters said, "Oh, you don't have to worry about that doctor. Mom knows how much we love her. She knows how much we appreciate all she's done for us." My response has become to that, "well good. Then it will be easy for you to get in there and say it. You know, no mumbling allowed. This is one place where being redundant is a virtue."

Dr. Martin Samuels:
If you're just tuning in, you're listening Inspired to Act on ReachMD Radio channel for medical professionals. I'm your host, Dr. Martin Samuels, and joining me today is Dr. Ira Byock. We're discussing the real issues behind end of life care and what individual physicians can do.

You know in the face of the President's efforts to revamp our healthcare system, there's been enormous amount of really hostile rhetoric in which people bring up this idea of death panels and so on, I mean why do you think people are so polarized over this issue with dying?

Dr. Ira Byock:
Well, a couple of things. The death panel thing and killing granny, is really, I think, a bold political motivated effort to derail serious discussion. I can't dignify it with anything more than that. However, there is enormous distrust that is ambient within our culture and our society about how we die, and frankly about the doctors and nurses and the hospitals in which we practice. There's no question. You know, I've been doing palliative care now for many years, over 30 years, mostly through hospice and the last almost ten years in hospital based and other types of settings. On occasion, I will get nasty letters, really angry letters, from proponents of physician-assisted suicide who are angry with me because I refuse to sign on to legislation and publically endorse legislation to legalize physicians writing lethal prescriptions. At the same time, I occasionally get angry letters from the far right, pro-life groups who are angry with me because I am promoting things like advanced directives and I refuse to perform CPA on literally everyone, which is what they want, or put feeding tubes down in literally everyone.

Now these are two reasonably extreme positions. You know, legalizing assisted suicide on the one hand, requiring CPR and feeding tubes on literally everyone on the other. The only thing that really connects both poles of these deeply held passionate views is a distrust of doctors and nurses and the health systems in which we practice.

Dr. Martin Samuels:
The idea that doctors don't really have at heart, people's interest, but might have some other surreptitious motivation, is that right? The feeling that the medical people are conflicted in some way?

Dr. Ira Byock:
Absolutely. The proponents of assisted suicide will say, "Well, you're just trying to bill people way past any value," or "you folks in hospice and palliative care have some religious agenda that you're trying to promote," and on the hand, the far right, pro-life groups accuse us of promoting a culture of death, which is just offensive, frankly. And I have to say that the work that I and the people in our field of hospice and palliative care do, I believe, is the most life affirming work being done in America today.

We are all about promoting life, but you know, if you want to affirm life, one has to affirm all of life. And this time of life we call dying, is a part of full and even healthy living. Part of the reason that I am so delighted to talk with you this afternoon is that, in fact, I think that physicians really have remarkable opportunity, not just in service to the patients and families we directly care for but also to provide an example to our culture. It's time to really reclaim our ability as a profession to lead the culture in ways that we are uniquely positioned to do. I think that it's time that we helped our culture to grow the rest of the way up. You know, acknowledging that we will eventually die. And instead of avoiding that topic, at all costs, really begin to integrate dying within a full a healthy living for individuals and for families. That's, I think, our remarkable opportunity.

Dr. Martin Samuels:
There really is no need for physician-assisted suicide if one is actually trained to deal with the issues that go along with dying. And that's your view, is it not?

Dr. Ira Byock:
It is certainly the role of the physician needs to expand to help people to die well. There's a difference between alleviating suffering and eliminating the sufferer. Our work is in service of quality of life, in service of life throughout the course of human life. Really, my view brings me all the way back to my training as a family doc. I learned that human development exists through the full course of human life, for individuals and families. And what I think our role is as physicians is really to help people to grow individually and together, throughout the course of human life. And that includes through dying, family caregiving, death and grief. And if we do that, then we, as a caring profession, will have really discharged the full measure of our responsibility and the opportunities that we have to serve our fellows.

Dr. Martin Samuels:
Do you think we're training people appropriately in this regard? I mean, certainly I was not trained at all. I had to pick up what I know about palliative medicine, which is actually very limited, I'm embarrassed to say. We're facing the baby boomers generation, getting older now. Do you think we're ready for this as a profession?

Dr. Ira Byock:
No. I don't think we are at all. I think things have gotten better. We're certainly teaching more communication and more clinical ethics, in medical school and residency training, but far too little. You know, in fact, I really believe that in the main, we're still teaching a mid-twentieth century curriculum in a 21st century world. Medical students, still today, are required to take nearly 200 hours of obstetrics, even though very few physicians practice obstetrics and deliver babies or take care of pregnant women in practice, and those who do, all will have completed a training program in family medicine or OB/GYN.

And yet, we teach people very little, maybe 30 hours at the most, of anything related to end of life care, while 70 or plus percent of physicians contribute to the care of patients during the last year of life.

Dr. Martin Samuels:
I'd like to thank my guest, the Director of Palliative medicine at Dartmouth Hitchcock Medical Center in Lebanon New Hampshire, author and professor at Dartmouth Medical School, Dr. Ira Byock. Ira, thanks so much, for spending time with us this week on Inspired to Act.

Dr. Ira Byock:
Marty, it's been a pleasure, and I'd love to come back and talk some more.

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field of medicine, hosted by Dr. Martin A. Samuels.