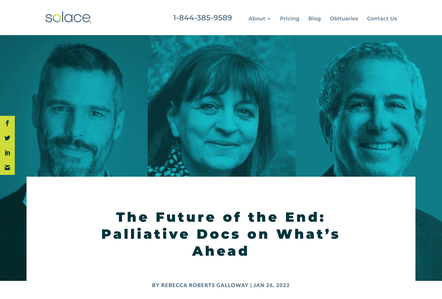

The Future of the End: Palliative Docs on What's Ahead

BY REBECCA ROBERTS GALLOWAY | JAN 26, 2022

The last two years have been anything but predictable. But as we move into another year, we look toward the future.

To help us understand what may be ahead for all of us as we reach the end of our lives, we turned to some of our favorite palliative care doctors to get their views on what we might anticipate in the years to come in health care, hospice, palliative care and their related fields.

Dr. BJ Miller is an author, physician and expert in serious illness, end-of-life issues and death and the cofounder of Metta Health, a telehealth-powered palliative care clinic.

Dr. Kathryn Mannix is a retired palliative care doctor and author now dedicated to supporting public understanding and discussion of dying.

Dr. Ira Byock is an author, leading palliative care doctor and the founder and Senior Vice President for Strategic Innovation at the Providence Institute for Human Caring.

In the future, will we see a change in the diseases now most often responsible for ending our lives?

BJ Miller:
"There is so much research into cancer, that I wouldn't be surprised if we continue to make strides or maybe even have breakthrough moments, where once incurable cancers become curable. I believe if medical science has its way, we'll continue to make strides there. So, that opens the door for other illnesses to make their way into the top two or three of hospice enrollment diagnoses. Progressive neurological diseases are on the rise — dementia, Parkinson's, MS — I think those have been out of the hospice fray in a lot of ways because they have a much longer period of disability and it's been tricky to serve them. But hopefully, between a change in policy and awareness and increasing numbers of people dealing with dementia, I think we'll see them more commonly in hospice in the future."

Ira Byock:
"Our treatments are getting ever more elegant. With cancer, the immuno-based, highly specific, genetically-based treatments are zooming forward at a remarkable pace of development and getting ever more effective.

Before long, in heart disease and kidney disease, and even liver disease, the transplantation of organs or the growing of human organs in animals like pigs with minimal need for anti-rejection drugs will be a reality. (Note: Not long after our conversation, U.S. surgeons transplanted a modified pig heart into a human patient for the first time).

So too, mechanical hearts may be around the corner. All of those advances may provide us with leaps in life extension for the most common causes of death today.

Dementia is an exception. I don't see anything on the horizon that's going to change the trajectory of dementia. So while we may fix their hearts, kidneys and lung problems and they may live longer, they may still be affected by dementia."

Kathryn Mannix:
"We've been very, very focused in the UK on cancer and being a cancer service. We now are at least a 50 percent non-cancer service in palliative care in the UK. Cancer is becoming more of a long-term condition for a lot of people.

Dementia is on the rise, about four or five years ago, it became the predominant cause of death in older women in the UK. So it is part of the idea that we're going to have to die of something. And the longer we survive, the more we will die of failures to repair our organs, and the hardest organ to repair, the organ that does not regenerate, is the brain. The longer we live, the more likely we are to develop cognitive failure.

And I think one of the difficulties is that dementia has become that 'd-word" in the same way that cancer was once the 'c-word." We can't name it, we can't talk about it, we notice our friends or relatives cognitively changing, but we don't like to mention it. And so we make the diagnosis late, we miss the boat for the few drugs that can make a difference in slowing the process down, and because we are afraid to talk about it, we're also afraid to talk about planning ahead."

For the first time in a long time, both the U.S. and U.K. saw declining numbers in life expectancy. Will the numbers head back up?

BJ Miller:
"It was a stark and telling moment. As troubled as our health care system is, one of the ways we pat ourselves on the back and convince ourselves that we are still doing amazing things is our life expectancy is high and it is going up and up year after year and now it's not.

My assumption would be that we're not making inroads in the social determinants of health — poverty, housing and other things that affect people's lifespan. We know if you are 20 or 30 miles outside of a city center, for example, your life expectancy goes down and there are signals that suggest that it has something to do with your proximity to care and to other human beings.

I think we have a lot of work to do in this country on equitable access and telehealth will help us get into the rural settings.

There are some forces to help us shift that, but as long as the health system fails to see the entwining of the social and medical issues, we're going to stall out in terms of progress.

If we really turn our attention to social determinants of health and access and get people more engaged in their health, these things will get us back on the road to progress. I'm cautiously optimistic."

Ira Byock:
"I certainly hope that we'll finally start to resolve the epidemic of deaths of despair, suicides and overdoses and gun violence. I think all of that is unbelievably regrettable, avoidable and unnecessary.

I do think life expectancy will continue to rise and I don't think it is outside the realm of the possibility at all that people will be living to 150 years of age. I think, with the exception of dementia, we have a really good chance of extending life expectancy for people with severe heart failure, kidney failure, cancers."

Kathryn Mannix:
"I think probably what we are going to see is life expectancy at birth hovering, dipping and rising according to how much we manage to get our act together to live healthier lives. But the truth is there is still 100 percent mortality to the condition of being human. What palliative care is about is not about the age at which you are dying, it's about how well you are living during the whole of your life.

It doesn't really matter whether somebody is dying of a genetic neurological disease in their teens or a person is dying of dementia in their 90s. It's about living every day the best that we can to live well. If we focus on dying, death, mortality rates, we are missing where the action is. The action is about us being alive and sucking the juice out of every single day the best way we can."

What new developments in medicines, technology and/or design would you like to see that could change health and end-of-life care in the future?

BJ Miller:
"I would like to see changes in durable, medical adaptive equipment — all the stuff that helps those living their life with a chronic illness or disability that can make or break the quality of life for someone. I'd like to see adaptive equipment kick it up another notch. The kit of parts we have having for decades is not designed well. It is ugly. It's not very functional. They don't work hard on improving the products because there's not much competition for it. If you need it, all of a sudden the attitude is, "You've got to wear these orthopedic shoes, so we're not going to give a damn how they look. Just take them and shut up." I'd like to see the mindset of bringing design and beauty into durable medical equipment, stuff you'd actually delight in using — prosthetic legs, canes, wheelchairs, mobility devices."

Ira Byock:
"Psychedelics medications can be used in a serious fashion, under careful screening, preparation and guidance, as a therapeutic modality. This is not really new. Psychedelics have been around since the early 1950s and only became controversial during the Vietnam War when they became associated with opponents of the draft and the war. That lasted more than 30 years.

Now, two generations or more have passed, and the FDA and the academic community is taking a fresh look at the medications and finding that when used carefully, they can be powerfully therapeutic. We are experiencing a dramatic increase in interest and support for the research and prescribed use of psychedelics."

Kathryn Mannix:
"On either side of the Atlantic, now as people become older and physically more frail, they gradually become more and more secluded from the world and live in communities of people of a similar age.

I'd like to see us become more socially mixed, valued for who we are, and the world around us designed to suit our aging population. We need to look at the design of our housing — the places where we live — so that traffic doesn't change so quickly that you can't get across the roads, that curbs are appropriately dropped so that people who aren't mobile can still get out, that transport is provided so as people need it, they aren't terrified to give up their driver's licenses and can find a different way of being mobile and independent."

What future advancements might improve health and hospice care and our quality of life?

BJ Miller:
"I'm more interested in the shifting cultural mindset of how we engage health in each other, more the analog space. My nickel is on us as a people evolving how we think about aging, disability and death. I'm not a Luddite, but I don't see technology making all the difference here. I do see more democratizing of health, moving the point of service online or to pharmacies. Even libraries could be a great place to mete out health advice. Maybe we'll see this blend of the social and medical world, that's where I think the action is."

Ira Byock:
"What I see happening is a mixture of really highly technical medical care to fight our diseases and keep us living longer and living well in combination with sophisticated teams to help improve our quality of life and support our families so that for those of us who want to be cared for at home in the context of our families, we can do that. And for those of us who would rather be at a special care facility, like a hospital or in-patient hospice, we can do that with much better attention to our physical comfort, our emotional, social and spiritual well-being. The two are not mutually exclusive. We can walk and chew gum at the same time. We can provide really excellent curative, life-prolonging care on one side, and when that no longer makes sense, then we can provide the best quality for our comfort, quality of life and families."

Kathryn Mannix:
"This isn't really a medical conundrum. This is a societal conundrum. Here in the UK, we have recognized a loneliness epidemic. We have a minister of government responsible for the relief of loneliness. Almost all lonely people are elderly citizens. They are widowed, they are distanced from the next generation of their family or the generation below that is working and the active generation of their family. I'm not sure that living to a great age is the thing that as a society is the best thing to aspire to. I think that living well for our accountable lifetime which was threescore a ten a generation ago and now is reaching into the 80s.

I think we have a lot of work to do just living to the age that we are currently living to, and it is much, much more about the way we value people in society than it is adding years to life. It's about adding life to years."

Where would you like to see hospice and palliative care change in the future?

BJ Miller:
"I think we have a lot of work in the field of broadening the base of people practicing it, broadening what we mean by existential and spiritual health and really helping people dig into meaning and purpose in a new way."

Ira Byock:
"I'm hopeful that people as citizens and patients will become ever more engaged in shaping the future of the health care system, because right now money continues to be the driving theme in health care change. If we are active, we have a chance to experience much better care at really no more, and frankly, a bit less cost. I was active pretty close to the inception of hospice and have seen it expand dramatically and become much more sophisticated and available in almost every community. Well over 50 percent of Americans who died will be touched by hospice care. But the quality of hospice care in the last two decades has been eroding and that's because of money. I worry that seriously ill and dying people will too often be vulnerable to profiteering.

What we have shown is that we can deliver phenomenally good care, even in people's homes. We now have the knowledge, skills and technical expertise to do so. And, we know that doing so, even in the very most sophisticated, comprehensive ways, actually costs far less money than people dying in hospitals, certainly ICUs. Whether we can deliver on that value of higher quality at a lower cost at scale, is not yet determined."

Kathryn Mannix:
"What I'd really love to see in the next 50 years is that palliative care becomes seen as an equal specialty with other medical specialties like cardiology, renal medicine, and so on, and that it is perfectly normal to refer a person to a palliative care opinion in the same way as you might refer for a cardiology opinion. For us to be able to step up as equal partners who are funded in exactly the same way as the other services.

I'd like to see palliative care on a level playing field and have less gatekeeping by other doctors who are afraid of the conversation that may be unleashed if they have a conversation about palliative care."

Kathryn Mannix is the author of "Listen," a new book with advice on "tender conversations." Her previous book "With the End in Mind" shows the "unexpected beauty, dignity, and profound humanity of life coming to an end."

BJ Miller is the co-author of "A Beginner's Guide to the End." He and co-author Shoshanna Berger explain,"Our ultimate purpose here isn't so much to help you die as it is to free up as much life as possible until you do."

Ira Byock offers his take on the "crisis that surrounds serious illness and dying in America" and describes his quest to transform care through the end of life in "The Best Care Possible," his third and most recent book.

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