When I was a kid, I had an overwhelming fear of death. It was the kind of terror that you can't be talked down from, the kind of terror you can only hope to eventually learn to ignore. I became compulsive about avoiding the subject. I would close books when it came up. I would leave rooms when it was discussed. I developed obsessive mental protocols to manage the fear. When I would hear the word "death," I would automatically think, "no death," as if casting a counterspell. "Dying?" "No dying." "Dead?" "No dead." Death was too big a topic to simply ignore. It had to be banished. It had to be fought.
I have an easier time talking about death now, but I wouldn't call it a favored topic. So I was a bit apprehensive when I sat down to talk with Atul Gawande.


The inspiration, Gawande, says, was realizing that he didn't know how to talk about dying — nor did his colleagues. "What I saw over and over again is that mortality is one of the problems that we simply didn't deal well with. I didn't deal well with it. I didn't know how to break bad news to people."

And so Gawande set out to learn how to give people the worst news they would ever get. He interviewed more than 200 people about aging, living with terminal illness, and dying. I asked him to tell me what he learned.

1) What is death?
This might sound like an obvious question, but it isn't. You can define death a lot of ways. It can be the death of consciousness, for instance, which does not always come at the same time that the basic bodily functions shut down.

"DEATH IS WHEN OXYGEN NO LONGER IS ABLE TO SUPPLY YOUR BRAIN"

But we're going to go with the basic scientific definition here.
"Death is when oxygen no longer is able to supply your brain," says Gawande. "That's the final common pathway."

2) The best way to talk about dying is to talk about living
"The reason why I felt like I wasn't doing a very good job as a doctor is it felt like the choices I was giving a patient were, do you want the operation that gives you this tiny chance that you might be able to live longer, or do you want to give up?" Gawande says.

"What I recognized from following different people around who turned out to be really good at these conversations is that they were never giving up. They were fighters, but fighters for a different concept of hope — the hope that you would have as good a life as possible all the way to the very end, no matter what comes. You are often fighting to just have a good day today. And when you do that, if you sometimes ignore how much time there might be, the irony is that people not only don't live shorter, they often live longer."

In a way, Gawande's critique of American medicine is that it's so focused on battling death that it's forgotten to prize life. Doctors focus too much on what a last-ditch operation might achieve, and too little on what it might cost. And even when no further interventions are planned, there's a tendency to view the decision as some kind of surrender, rather than as an effort to give someone the highest quality of life they can have in their remaining days. "The goal is not a good death," he says. "The goal is how do we have as good a life as possible all the way to the very end while coping with the fact that we are biological creatures, that we are flesh and blood and are going to have limitations as we go along."

3) Less medicine doesn't always mean less life

The way American medicine usually frames the question of end-of-life care is, do you want doctors to do absolutely everything they can to extend your life, even if those interventions may be horribly painful, or run the risk of terrible complications, up to and including death? Or do you want to give up on the possibility of extra time in
order to avoid the pain, suffering, and possible complications of those interventions?

**THEY HAD LESS SUFFERING AT THE END OF LIFE. AND THEY LIVED 25% LONGER**

Gawande doesn't buy it. "There's a study — and now there have been a bunch of these — but the most scientifically-done one randomized people at Mass General hospital with Stage 4 lung cancer to either get the usual oncology care, or get the usual oncology care plus a palliative-care specialist who discussed this thing that we don't want to discuss. The ones who had that discussion ended up stopping chemotherapy sooner. They ended up choosing hospice earlier. They had less suffering at the end of life. And the fascinating thing is they lived 25 percent longer."

That seemed to raise the possibility, I said to Gawande, that there was a win-win here: less aggressive interventions at the end of life might, surprisingly, mean more life, as well as less pain. He agreed. "When we use the $80,000 drug as the fourth line of action, all you get is the harm. You just get the toxicity. And you get none of the benefit. And the result is the average person, when you're taking it at that stage, it ends up sacrificing everything that they were trying to live for, and in fact, sacrificing time. So yes, it's a win-win deal."

4) **Talking about death is a skill. We should reward it.**
One reason there's more surgery and less discussion is that the health system will pay a doctor a lot for doing a surgery and basically nothing for having a frank, sensitive, hard conversation about end-of-life choices. Of course, doctors have those
conversations anyway, every single day. But a side-effect of the economics is that doctors don't have much incentive to learn about how to have those conversations. There's good economic reason to go to fun conventions in beach resorts where you learn about new drugs and new devices and new surgeries. But no one puts on fabulous conventions about end-of-life discussions.

NO ONE PUTS ON FABULOUS CONVENTIONS ABOUT END-OF-LIFE DISCUSSIONS

"We really reward me for being a surgeon," says Gawande, "and this debate about whether we are going to make it possible for people to be rewarded for being really good at these human sides of the skills. I think is a really fundamental part of this debate."

5) The nearer you think you are to death, the more your priorities change

"I describe the research of a woman named Laura Carstensen at Stanford, who studied people ages 18-94," says Gawande. "Young people basically aspire to achieve, to get, to have. They're willing to delay gratification. When we become aware of the fragility of our life and we get older, we focus on a narrower group of friends and family. We become much more focused on intimacy and deeper relationships with folks and being connected to a few things that make us feel purposeful in the world. And that can change overnight."

WHEN YOUNG PEOPLE FEEL DEATH MIGHT BE NEARER, THEIR PRIORITIES SHIFT

What's interesting about Carstensen's research, Gawande
continues, is that it really is about mortality, not just age. When young people feel death might be nearer, their priorities shift.
"During 9/11, she did some research and found that young people all moved to the older signature. We all wanted to be with family. We wanted to focus on a few people, that we wanted to make a difference for them and not just the broad world. And three months later, we were back to being like, yeah, this is all fine."

At about this point in our discussion, I brought up Ezekiel Emanuel's essay (http://www.theatlantic.com/features/archive/2014/09/why-i-hope-to-die-at-75/379329/) explaining why he wants to die at age 75. The argument he makes is really about achievement: once his capacities begin to diminish and he's unlikely to make further major professional contributions, Emanuel's view is that life, at least to him, loses a lot of what makes it worth living.

Gawande counters with Carstensen's studies. "The studies like Laura Carstensen's show that as that [aging] happens, people are not becoming more unhappy. They're actually, in general, less likely to be depressed, more likely to have more complex emotions that you don't have at a younger age. You shift from trying to win that Nobel prize to realizing that that didn't matter so much, and what you really care about is being close and connected to my family and a few friends."

6) Even the dependent want to be independent
Though priorities in old age might shift toward close friends and family, it's actually not the case that the elderly want to live with their families. This was a bit of a surprise to me: I've read a lot of laments about how, in the West, the elderly don't live with their
families, and so end up isolated and unhappy. The data tells a more complex story.

"As we got pensions and Social Security, the very first thing that families did is they moved apart," Gawande says. "The parents did not want to live in the home with their son or daughter and follow their rules, and the son and daughter did not want to keep living with mom and dad telling them what to do. Sociologists call it 'living at an intimate distance.' Near, but not too near, is kind of the idea we aspire towards. This is happening all over the world. People are increasingly likely to live into their old age alone and want to have that preserved. It works great until you can't be independent anymore."

7) Nursing homes are some of the saddest, most innovative places in the world

"The people who are changing the way we build nursing homes, I think, are some of the most innovative people in America right now," Gawande says. "You know, we talk about the technology innovators. I mean, these people are doing things that I think will affect us in far more important ways."

Nursing homes, right now, are built to emphasize the word "nursing" rather than the word "home". At the center, typically, is a nursing station. But nursing home reformers are trying to change all that and to build them around kitchens. And that's where it gets tricky.

"In the kitchen," Gawande says of this new breed of nursing homes, "you could go to the refrigerator and get whatever food you want. That is unbelievably controversial, if you can imagine, because people will say, well, you know, a diabetic person might go to the refrigerator and take out a soda and that's not safe. An Alzheimer's patient might go and take something out besides the pureed food they're supposed to be on."
"YOU'LL SEE ALZHEIMER'S PATIENTS HOARDING COOKIES. GIVE THEM THE DAMN COOKIE."

"We make these choices all the time in our home and taking those away from people takes away really fundamental things about who they are, what makes a life worth living. The biggest complaints about patients in nursing homes — by the way you can get a report filed against you in a nursing home — are about violating food rules. So you'll see Alzheimer's patients hoarding cookies. Give them the damn cookie. They might choke on it, but what are we trying to keep them alive for? Let's allow some risk, even in the Alzheimer's patient, to be taken."

8) One problem with old age is that nursing homes market themselves to the young, not to the old

"An expert gave me this quote that has really stuck in my mind," Gawande says. "Safety is what we want for those we love and autonomy is what we want for ourselves."

Nursing homes know that. And they also know that, more often than not, their customer isn't the person moving into the nursing home — it's the younger relative who's managing the move. "Whether it's a home-health agency or an assisted-living facility or a full 24-hour-a-day nursing home, these places market themselves to our desires, not to our parents' desires, because more often than not, we're the decision makers. So we bring the parents around and they will tell us, 'We are incredibly safe,' and that's what we want to hear. But how lonely are people there? How purposeful are their lives?"

"SAFETY IS WHAT WE WANT FOR THOSE WE
“Love and Autonomy is What We Want for Ourselves”

“People experience these as prisons. As people get older they get lower levels of anxiety, higher levels of happiness, until you put them into these institutions, and then that's when you see the three plagues of loneliness, helplessness, and boredom.

“You know, people don't want to play bingo and be comfortable all the time. They want to know that they have some things that connect them to who they are. But that is not what families are asking about. And so the result is that we get places that end up reconstructed to look like more and more like hospitals, instead of like homes where you can go to the kitchen and get what you like.”

9) Where we die is changing — fast

“In 1950 in the United States,” Gawande says, "the majority of people died in their home. And the reason why is they didn't see that there was much likely benefit of going to a hospital. But we discovered a ton of stuff in the last half-century so that by the end of the 90s, 83% of us died in an institution, most commonly the hospital. And only 17% died in the home. That was out of faith that there was going to be something that could be done.

“But as prosperity continued to rise, we began to expect that we're going to have some control and some quality of life and there's been, in the last 5 years, this countervailing force. We're closing in on 50 percent of people now dying in hospice, either at home or in a hospice center outside a hospital.”

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