

# Atul Gawande's 5 Questions to Ask at Life's End

The surgeon and writer wants to guide a new kind of care in America

By [Sue Campbell](#) | February 10, 2015 | [Caregiving](#)

Everyone deserves to be asked five questions as they face life's end, Dr. Atul Gawande says. And if families and doctors learn to ask and then really listen to the answers, he believes, care in this country will radically change.

I spoke to Gawande the day his [documentary film about end of life](#) was to premiere on PBS's *Frontline*. The movie is based on his bestselling book, *Being Mortal*. Both the show and the book add to a growing national conversation about aging well and living fully when you have limited time. More and more, the focus is on [what those facing their own mortality want](#) — not just which treatments will extend life.

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“We tend to assume that safety and health are paramount, without asking: ‘Are you lonely? What would you like?’ And if the Alzheimer’s patient wants to eat 40 cookies, that’s not necessarily good for him — but I want to say, ‘So what?’ That’s living,” Gawande said.

Gawande has a unique vantage point as both surgeon and son. His father’s life — and death — were the inspiration for his examination into end-of-life issues. He also drew from experience treating patients and from about 200 interviews he conducted to create a systematic approach that gives patients a feeling of relief and sense of control.

Now, through his research lab, Gawande is training doctors to ask the five questions and testing and measuring what changes for patients when they do. The goal is to scale the approach so it becomes part of routine end-of-life care for patients.

Here are excerpts of our conversation, edited for length:

**Next Avenue: Can we rely on medicine and doctors to help patients focus on living as they choose?**

**Gawande:** I don’t think it’s going to come through medicine. I don’t think we’ll make it better because doctors require it to be better. It will be because patients and families realize there’s a better way to deal with the last days of our lives. That doesn’t mean you give up on getting the treatments you want; it means you look at the priorities that are most important to you. That’s what we have not followed through on.

**What’s an example of discovering priorities?**

There are several stories in the film and book. One is about a woman who has been under treatment for two years for a cancer we know isn’t curable. We finally ask about what really matters to her, to make sure she gets to be able to do it if time runs out. We learn that she wants to take her grandchildren to Disney World — but by this time, it is too late. She dies just

a few days later. If we had known and known soon enough how important this was to her, we could have ensured that it happened.

### **It's fundamentally about what patients want?**

A lot of these moments hinge on the fact that people do have priorities in addition to living longer. The most reliable way to know what those are is to ask, and we don't ask. We ask less than a third of the time.

It's amazing, with the documentary, to have the camera in rooms, to see the conversations doctors, patients and families do have — and *don't* have.

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Up until now, your *Checklist Manifesto* was probably your best-known work. That's about the list you created to make sure surgeons followed a system to operate on the right limb, for instance, and to ensure communication on the surgical team. Is this new approach to end-of-life similar?

I see it as completely similar. It's really a series of questions that we need to be comfortable asking one another. It needs to be normal to ask these questions, especially when someone is faced with a serious illness, and especially when we know that we're aging and becoming frail.

We need to know:

- What is your understanding of where you are and of your illness?
- Your fears or worries for the future
- Your goals and priorities
- What outcomes are unacceptable to you? What are you willing to sacrifice and not?
- And later, what would a good day look like?

Asking these allows everybody to understand what the goal really is — what are you really fighting for? It's for a life that contains certain things.

When I asked my dad these questions, he was very clear that he wanted a social life and he didn't want aggressive treatment that would prevent him from being social. So if his tumor was going to make him a quadriplegic, he didn't want to be on a ventilator or have a feeding tube.

### **When should families and doctors use this list?**

The conversation has to happen well before the end. Too often, a crisis is when we have this conversation. And you need to ask repeatedly — people change their minds.

### **How does using your list change care in a broader sense?**

I run a research center, Ariadne Labs (a collaboration between the Harvard School of Public Health and Brigham and Women's Hospital in Boston), where we devise and run tests on a large scale.

I practice at Dana-Farber Cancer Institute, so for this end-of-life approach, we are working with doctors there to train them in asking these questions. We have doubled the number of conversations people are having. And the results of the doctors who have the conversations vs. the ones who don't is that the anxiety levels of the patients with trained doctors drops.

These are people with great experience; many of the doctors have been practicing for 10 or 20 years. But the norm is to give people facts, the pros

and cons, data. But the palliative care people are telling us that it's what people tell you is their understanding of the facts — along with their hopes and fears — that really matters.

This is not just a conversation doctors have; any family can have it, too. It's not just about the last weeks of life, it's about the last decade. We are all going to spend a significant part of life with our health getting worse, we'll get frail and have more illness — and that is a victory. We get an extra 20 years after age 65, the bonus years. What's acceptable to us and what's not? That's the conversation that has to become normal in our country and in the world.

### **How do you train the doctors?**

The way we've done it, and we have to figure out how to scale it, is the doctors have their normal type of conversation with an actor playing a patient. Then we have them use the questions, and see how it feels. It gives them practice getting the words out and teaches them to be silent a little more and to let the patients have their say.

When I first tried this myself, one doctor told me I was an explain-a-holic. I had to learn to take no more than half the time talking and to ask the patients what they understood and what were their concerns.

### **What if you try to have this [conversation with a parent](#) and they don't want to discuss it or haven't thought about any of these things?**

It's normal that the first time you raise it, someone's going to say, 'That's not relevant right now,' or 'We don't need to think about that.'

Thinking about mortality is anxiety provoking. But — you've opened the door. You don't have to have that conversation the very first time you bring it up. You started it, and often, they are processing and later become ready and willing to talk about it.

**But it's still awkward to bring it up.**

I'm hoping the film and book gives people a reason to talk. In the book, I talk about the man who says he will be OK as long as he can eat chocolate ice cream and watch football — and that experience became part of the conversation I had with my dad. I mentioned it, and he said, 'Well, that wouldn't be enough for me. I'll tell you what I want...' That opened the door.

You will get shut down, but another moment will come.

*Note: Follow Gawande's ongoing Twitter conversation based on the Frontline special, by searching for #whatmattersmost*

**Sue Campbell** was an Editorial and Content Director for Next Avenue. Follow her on Twitter [@SuePCampbell](#). [Read More](#)

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