

Tricia Johnson (00:03):

It's Aspen ideas to go from the Aspen Institute. I'm Tricia Johnson, author and surgeon, Atul Gawande has written about healthcare science and aging lately. He's been focused on love. He wants to spread the message that everyone has equal worth from a convicted felon to a hospice nurse. It's especially hard to remember right now. He says,

Atul Gawande (00:25):

I'm where we have a hard time even saying our neighbor has equal worth at the root of it is shutting off our curiosity about people's lives,

Tricia Johnson (00:35):

Aspen ideas to go brings you compelling talks from onstage events, hosted by the Aspen Institute. The Institute is a nonpartisan forum for values based leadership and the exchange of ideas today's discussion is from spotlight health. In his recent writing, Atul Gawande is exploring a major societal problem. He sees a gap between our aspiration for how we treat each other. And the reality of it, Gawande who wrote the book being mortal describes how we can bridge the gap in this conversation with Lucy Kalanithi. She's a professor of medicine and the widow of the late dr. Paul Kalanithi, who wrote when breath becomes air here's Lucy Kalanithi.

Lucy Kalanithi (01:17):

Good morning, everybody. Please help me. Welcome surgeon researcher, writer, thinker, and moral leader. Dr. Gawande

Atul Gawande (01:33):

[inaudible]. And please help me welcome Lucy Kalanithi. Who is a physician, uh, grieve formerly grieving, still grieving wife, uh, from a B of a beautiful book by Paul Kalanithi when breath becomes air and, uh, and also a deep thinker. Thanks. And to lift things up a bit, we're going to talk about death.

Lucy Kalanithi (02:04):

I feel so lucky to be sitting here with you. I think everybody in this tent feels the same way. I know you as someone who is kind when you don't have to be, you wrote a blurb for Paul's book. Well, before it came out or was anywhere. So thank you for doing that. I think it would have meant the world.

Atul Gawande (02:19):

Amazing, amazing unputdownable book. Thank you.

Lucy Kalanithi (02:24):

So I'd love to ask you first about some of the biggest themes in your writing. Um, you've always been grounded in compassion and humanity, but this year that actually seems amplified including on your Twitter feed, which is a lot about injustice. And you recently gave a commencement address where you talked about how the hospital is one of the few places where you can see the whole range of society, which I think is one of the most exciting things about being a physician too. And you said over and over in that talk, that the foundational principle of medicine is that all lives are created equal. And then when you look back across your, you wrote complications in 2002, you were still a resident you've written three books since then your essay, um, the cost conundrum was required reading for Obama's oval

office, being mortal spin on the New York times bestseller list forever. And, um, you have this great ability to hit the Zeit Geist, tell us where we are and then tell us how we can get better. And looking across your themes over the years, it seems like you started out writing about safety, and then you wrote about quality and then value. And now you're sort of writing about love. And I'm curious, what is it about this particular cultural moment that is making you so interested in talking about compassion?

Atul Gawande (03:45):

You heard it on the stage just earlier. There seems to be a deep gap between, um, that that I've always been interested in, in between, um, our aspiration for how we treat each other or aspiration about for what we believe and the reality of it, and, uh, mining and depicting the reality. That gap has always been powerful to me. Um, the medical principle that we talk about goes back millennia, which is at all lives have equal worth. And to try to really explain what that means in that commencement address. I gave at UCLA, I talked about treating your prisoner, who had come in and with a, with a female, uh, chief resident, I was the medical student and he more or less verbally assaulted her, uh, was menacing in ways that I don't really want to quote here. Um, and it was not safe for her to participate. So she hands the clipboard to me and says, you take care of him. And he'd swallowed a razor blade and had, uh, slashed his wrists and, uh, needed to figure out how to take care of him. And it was one of those moments when you ask, what does it mean to say all lives have equal worth?

Atul Gawande (05:10):

How do you and I was speaking to medical students, how can you be in a position that you will say this person still has equal worth? And we're in a moment where we have a hard time even saying our neighbor has equal worth and that at the root of it is shutting off our curiosity about people's lives. And I think that, um, what's beautiful about your and Paul's work cause it was your impulse work. Um, in asking about mortality, a lot of what interests me, it comes out of medicine is the fact that we close our eyes to the ways in which we're all vulnerable. We are all finite. We are all, um, uh, imperfect. And, uh, and we are even across the me too movement trying to grapple with how do you live with the worst of who we are and the best of who we are and know that for every human being, we are not defined by either one of those things.

Atul Gawande (06:19):

We're not defined by the worst thing we do. And that's what we're trying to say about prison reform, but we are also not the best thing we do. I, I, I, I try to act like I'm the best thing I can, I get to write in my best voice and, you know, be the person my mom wants me to be, but, but, but you're kind of, you know, you're all of it, you're all of it. And, and, and, uh, and so I think what is powerful and what I wanted to ask you about, um, in this conversation is that you and Paul put yourself out there in the course of his grappling, with his own mortality, the reality of what he thought he would aspire to be, what you thought you would aspire to be. And it was like opposite it's in those very personal moments that it becomes really alive, right choices. Like, should we have a baby when he is, um, has a brain tumor that, you know, can't be cured, a quest, a decision that could be questioned by anybody and everybody

Lucy Kalanithi (07:26):

Including us. Yeah, it was. Yeah.

Atul Gawande (07:29):

And so I want to ask, what were you, what do you think he was aiming to do and what were you aiming to do? Um, to me it felt like reminding much of the same thing. There's the, there's the fantasy world of how you think the world is. And then there's the reality. And there are moments whether it's what's happening at the border, whether it's a moment of, uh, incredible disempowerment because of, uh, sexual harassment or because of getting a diagnosis that suddenly alienates you from even the people around you and finding you're isolated and not able to connect. So maybe you could tell us a little bit about what led to that and how you see it connecting here,

Lucy Kalanithi (08:14):

What led to figuring out what was important or having the baby, or

Atul Gawande (08:17):

What led to the, what led to writing in that moment and being so vulnerable, his being so vulnerable, and then you're adding your own voice to that.

Lucy Kalanithi (08:26):

Sure. Um, so my late husband was a, uh, neurosurgery chief resident at Stanford when he was diagnosed with stage four lung cancer, um, and lived for 22 months after that diagnosis. Um, and when he was diagnosed, actually he wrote to his best friend who, um, uh, and said, you know, I'm, uh, I have some bad news to tell you, I found out I have terminal cancer. Uh, the good news is I've outlived two Brontes Keats, and Stephen Crane, the bad news is I haven't written anything. And that this is a young neurosurgeon who the real loss is that he hasn't written. He sort of had this distant dream of writing, very fortuitously, ended up writing an essay and then getting a book deal and, and finding that to be what he wanted to do. And he said, um, the book, uh, pillar Tinker's Creek by Annie Dillard, sort of a close study of nature.

Lucy Kalanithi (09:17):

And the, you know, when I said, what are you hoping to do with this writing and this book? And he said, you know, I want to do what any dealer did for nature, but I want to do that about dying and just talk about what it feels like and what I'm thinking about as I'm going through this. And some of that was a diary, like the act of being so close to what's happening, um, you know, and trying to seek, how long do I have left and reading through these statistics? And he said, you know, looking for solace in statistics right now is like trying to quench your thirst with salty water. Like this is a big mortality is not a scientific it's visceral. Um, and you know, I think it's funny, cause I think in medicine so much of what you're asked to do over and over is rise to the occasion.

Lucy Kalanithi (10:05):

So you deliver your first baby, you do your first surgery. The patient may not know it's your first time you tell somebody they're dying. And I think you just keep rising to the occasion over and over. And this was a little like that. It was like, Oh, turns out this is what we're going to have to do together. And, um, you know, act in these circumstances now. And then for me, um, after Paul's death, I started on this book tour on Paul's behalf and started out talking as a sort of vessel for Paul, um, and then added in talking about grief and then added in talking about end of life care, physician burnout. Like there's so many different. One of the other big deaths in Paul's book is, uh, is a dear friend. Who's a surgeon who jumps off a building and dies. And, and so there's all these different things in healthcare and medicine that are so deep and soulful that connect to our real lives. And I feel like getting to write and talk about

those was a big surprise and has been so fulfilling and different, um, from what we thought we would do. And then also helped us make sense of a very confusing, scary situation.

Atul Gawande ([11:17](#)):

I want to put the context of when, when, when breath becomes air came out, my book was being modeled. It came out about six months, seven months before that, and put a little bit of a pin in where we were in society at that moment, because at that time it was still the peak of the death panels claim, a highly politicized moment where to have any discussion about what happens at the end of life. And to say that there should be a discussion between the patient and the clinician was seen as tantamount to violating your ethical principles as a physician. It as if you were saying that, um, people are being asked to systematically, let people go across the country as if it's a kind of genocide or something like that, that we are attempting to do. And what I felt when I read that, yeah, the manuscript, um, as my book was coming out was they were speaking from the same place and that same place was.

Atul Gawande ([12:17](#)):

Um, and, and I didn't understand when I was writing my book, what was wrong, why I'm a cancer surgeon and why I often felt my, um, ability to handle situations where people had problems. I was not going to fix. Uh, I often came out badly. We would try all kinds of heroic stuff and it would just seem like we only left suffering behind us. And what I learned from interviewing lots and lots of people, um, and hearing their stories and seeing exactly what happens at that really sharp end of, of what happens. He was so observant about his experience in the same way is that people have priorities in their lives besides just survival, that priorities for their quality of life. And you start finding out that discussing death is really about discussing life in the face of mortality and that we are all mortal.

Atul Gawande ([13:07](#)):

And that it's really a book about living, knowing that you have, uh, uh, I find a time on the earth and during that time, your priorities, what are you living for? And it became really acute in that moment for Paul. But, um, when, when you ask and it really, you really realize it's not just about what happens towards the end, it's throughout your life, as you grapple with the reality of, um, your own imperfection, your own vulnerabilities over time, your own illnesses and, and your own, uh, you know, art. I thought my goal as a clinician was health and independence. Um, that our goal is to keep you healthy and independent, but then what's the goal. When you, when you're, you can't be perfectly healthy and you can't be independent and you realize that the goals are whatever your priorities are for your quality of life, as well as your quality of life. And so there's certain questions we don't ask that he started asking, um, what's the minimum quality of life you would find acceptable.

Atul Gawande ([14:10](#)):

What's the, what are you willing to sacrifice? What are you not willing to sacrifice in the course of care or in the course of your experiences out in the world? And then how do we make, make sure we're aligning what we do in line with that? Now we don't, we don't ask that question. I've been doing surveys now for three years with a coalition and find that only 25% of the time do people who are seriously ill or have a serious disability, have a conversation with a clinician about what their goals are, what, what matters to them most besides just survival. Um, and they have a remarkably different experience, but it's only 25%. I wanted to ask you because this quote has always stuck in my mind and I get to read it to you. And I getting to be here on stage. That's going to, this is a quote from Paul in the book.

Atul Gawande ([15:00](#)):

And I wanted to ask you about that moment of thinking about what his priorities are and what really matter. He said the tricky part of illnesses that as you go through it, your values are constantly changing. You try to figure out what matters to you, and then you keep figuring it out. And then he goes further. He says, you may decide, you want to spend your time working as a neurosurgeon, but two months later, you feel differently. Two months after that, you may want to learn to play saxophone or divert your devote yourself to the church. Death may be a one-time event, but living with terminal illness is a process. What did you discover? Because it was journey were his priorities. And what did you discover your priorities were?

Lucy Kalanithi ([15:44](#)):

Um, yeah, so that moment of diagnosis, um, was such an explosion because you realize how much of your identity is tied up in your future self and who you imagine you will be years down the line and choices you're making today are very much related to you in the future, that all disappeared. And it really was a process actually, as treatments worked for a while and then failed, and Paul's physical state changed. He worked for a neurosurgeon, worked as a neurosurgeon for a year, and then couldn't and started writing. And we had our child and he actually has sort of had it in his mind as, um, give me 10 years. I want to be a neurosurgeon still give me one year. I want to write a book, give me a few months. I want to spend time with my family only and kept actually adjusting to that.

Lucy Kalanithi ([16:36](#)):

It was pretty, it became pretty clear, but it took a while. Um, and then my goals, you know, at that time, my goals were partly to help him avoid unnecessary suffering. And as a physician, I knew that it's very possible to suffer, um, in ways that will not help you. And, um, the big example was at the very tough decision at the end of Paul's life, that he didn't want to go on a ventilator because his clear goal at that time was to be mentally lucid and life without that was not what he wanted. Um, and then I think my goal was to learn how to understand suffering. And that was a couple of ways. I mean, I started to feel like I'm not sure there's a point to human suffering, except for it connects you to all other human beings forever now and forever.

Lucy Kalanithi ([17:30](#)):

And I started to notice suffering and feel connection to it elsewhere. And I thought about, you know, um, I think about this in raising a child now, too, she's over there, she's four and she's being very quiet and good. So we, my dad and I used to think, you know, I want to raise a happy child and now I think I wanna raise a resilient child and they're kind of different. And, um, you know, when Paul and I were deciding to have baby at the time, um, we talked a lot about it and I actually tried so hard to find Andrew Solomon yesterday. Cause he was here because reading his book far from the tree, um, made me understand why it was okay to have a baby and introduce that uncertainty and paint a thought. I don't know if I can withstand like this sick husband and the baby. And I was like, you know, what tough things happen. And we love each other through them. And I think if we have capacity and support, it's a possible to do this. Um, and I think anybody who has a child is thinking, you know, can I give this child a good life? Um, you know, and is this important to me? And th those circumstances were not different in this new world that we found ourselves in. Um, yeah, I think that's mostly it. And I think, can I quote you back to you?

Speaker 4 ([18:44](#)):

Okay. So no.

Lucy Kalanithi ([18:53](#)):

Oh gosh. And, and so your book being mortal the first half is about aging. The second half is about dying and those are the two things that medicine can not fix. Like you just described. And you talk about what it means to be a doctor for people whose problems you cannot fix. And there were some sentences from that book that I carried around, like a little talisman and my favorites, um, were these it's five sentences. As recently as 1945, most deaths occurred in the home by the 1980s, just 17% did we've allowed our fates to be controlled by medicine, technology and strangers, but not all of us have that takes. However, at least two kinds of courage.

Speaker 4 ([19:40](#)):

The first

Lucy Kalanithi ([19:40](#)):

Is the courage to confront the reality of mortality, the courage to seek out the truth of what is to be feared and what is to be hoped when, when a seriously ill such courage is difficult enough, but even more daunting is the second kind of courage, the courage to act on the truth we find.

Lucy Kalanithi ([20:02](#)):

And I remember reading that and thinking that is the task like that is the thing that Paul and I want to do, which is figure out, go clear eyed, like what is really happening to your body. And then how do we shape your medical care? So that it's built around what actually matters, which is not any treatment at any cost. And I think being doctors, we had a clear understanding that that goes against American medical culture to do that. And you really have to ask questions and you, we talked this morning, you may have to bring up those conversations with your own doctor. And by the way, you talked about how only 25% of patients get a conversation like that. And you in your serious illness, conversation guide are teaching experienced physicians. And I think medical students and all the Massachusetts medical schools, how to do that.

Lucy Kalanithi ([20:52](#)):

And thank you for doing that. It's, um, it's nothing short of a revolution, I think. Um, [inaudible] and I'm curious to know from you, so as physicians, we sort of get a front row seat to the human condition, which is so beautiful, but in writing, being mortal, you actually got, you went further than that. So you went into patients' homes, talked with bereaved families, um, learned from people what really was most important in their most difficult moments, including with your own family. And I'm curious how the act of writing being mortal affected your own, thinking about your life and your choices or your mortality too.

Atul Gawande ([21:39](#)):

Um, I think through stories and through writing. So it, it, uh, many of, most of my writing is thinking out loud and, and getting to, um, getting to, to work my way through problems. I don't find, it's interesting to write about things where I'm just trying to explain something to people that I know the answers it's much more sing, like why the hell are our costs so high or, um, or what is going wrong in this space? And I'd guess I'd say there were two things that really struck me when you brought up suffering. And then I'll

talk about what my vision of suffering is for myself. Um, suffering, I, I came to realize was, um, no one asking you what matters to you, but telling you how they're going to treat you.

Atul Gawande (22:23):

It is what we're describing at the border. It is what we're describing when we're talking about lack of power to even guide your own career path. And it is what you're talking about in healthcare. When we, I, I did interviews with people who were in nursing homes, where I would just try to find out, um, what mattered to them and what was kind of heartbreaking. And the reality of seeing all of this is that, um, you, when you don't ask people what their priorities are, what we're doing to them ends up being out of alignment with what matters to them and the result of that is suffering. And so I'd see it in the nursing homes when, um, people would, for example, be not allowed to have a drink at the end of the day in the nursing home, when you would have, uh, you would be required to go to bed at a certain time and it's lights out and you'd wake up at a given time and there'd be a pill line.

Atul Gawande (23:20):

And the, you know, you have to get dressed in the, in the following way. You can't have your own furniture because it's not safe. Um, what does this sound like to you? Prison, prison. Exactly. And the most heartbreaking thing in my interviews was over and over again, people would say, when can I go home? When can I go home? Because a place where you can't make these choices is not your home. And we've medicalized the aging process to the point that when you go into nursing homes, places you need 24 hour care, they look like hospitals. And, you know, the revolution was, I described one guy, bill Thomas calls himself, a nursing home abolitionist.

Atul Gawande (24:04):

And he, uh, built an nursing home, built, built, built nursing homes for people who needed 24 hour care, but built it around a kitchen. Uh, you could have a pet, like, you know, pets are unsafe. Uh, but, but now you have something to care for and love. And because of that, the amount of anti-psychotic medication and antidepressants went down mortality, uh, survival went up and in those places you had a kitchen and in, it was a refrigerator and in the refrigerator, you could go in and you could take out whatever you, what you could take, whatever you want. Like what if a diabetic took a soda out of the refrigerator, this is where we're legally liable. If they take, if they drink a soda and their blood sugars high, and they go to the emergency room and creating the freedom to go in there and, and make a bad choice. And then we can argue with you about it. I met a woman who had Alzheimer's disease and, um, very advanced. And she was on a medically ordered pureed, only diet. And, uh, so she could only eat liquid food. And, um, uh, and so she would be calling hoarding cookies that she'd stolen from her neighbors and they confiscate her cookies. And then they'd write her up and they call the kids at home, the adult kids, you know, she's stealing cookies again. I just want to say, let her have the cookies.

Atul Gawande (25:33):

She's telling you what her joy is. This was one of them last joys that she has, and we couldn't listen. And we that across healthcare and that, and then you said, I do think this is very deep because I think we see it across society as we've get to live 80 plus years on average age, we're going to spend significant chunks of it with chronic illnesses, with disabilities and navigating life with incredible productivity. And an ability to contribute is navigating life with, with, um, your abilities and losses changes changing. And our goal has to be in how we live in care for people that it's not just about survival, that it's about, you're getting to do what Paul did, which is navigate the pathway of what is it that matters most to me, are



people caring enough to help me achieve those things. And then can we orient a system around doing that? And ironically, all of the evidence shows it's less suffering and it's equal or often lower cost with equal or better survival [inaudible].

Speaker 4 ([26:50](#)):

So we're out of time, uh, you have said better is possible. It does not take genius. It takes diligence. It takes moral clarity. It takes ingenuity and above all. It takes a willingness to try. Thank you for your willingness to try. [inaudible]

Tricia Johnson ([27:21](#)):

A tool. Gawande is a staff writer at the new Yorker. He's also the CEO of a health care partnership between Amazon Berkshire Hathaway and JP Morgan chase. Lucy Kalinithi is a clinical assistant professor of medicine at Stanford. She's the widow of Paul Kalanithi who wrote the bestseller when breath becomes air, their conversation was held June 24th at spotlight health.

Speaker 4 ([27:46](#)):

[inaudible]

Tricia Johnson ([27:46](#)):

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