Stephen Calabria: [00:00:00] From the Mount Sinai Health System in New York City, this is Road to Resilience, a podcast about facing adversity. I'm your host, Stephen Calabria, Mount Sinai's Director of Podcasting.

On this episode, we welcome Jeremy Boal, MD. Dr. Boal has spent decades on the front lines of healthcare, caring for patients in their homes, reshaping health systems, and working to build a more compassionate, equitable model of care.

But in 2023, his understanding of those questions shifted when he was diagnosed with ALS. As you'll hear, Dr. Boal reflects on what it means to confront mortality, not as a concept, but as a reality.

His journey demonstrates the true meaning of resilience and the power of perspective in facing life's greatest challenges. We're honored to welcome Dr. Jeremy Boal to the show.

Dr. Jeremy Boal welcome to Road to Resilience.

Jeremy Boal: Thank you, Stephen. Good to be with you.

Stephen Calabria: Could you walk us through your years in [00:01:00] medicine and what your particular focus was?

Jeremy Boal: Sure. I am an internist and geriatrician. I spent most of my career at Mount Sinai, where I was a resident as well as a geriatrics fellow.

I spent the first 10 years of my career co-founding and helping to build and run the Mount Sinai Visiting Doctors Program, which is a program for home-based care for people with serious and late stage illness. And then I went on to a number of other administrative roles.

I was Chief Medical Officer of the Northwell Health System, and then I came back to New York City to be the Chief Medical Officer of the new Mount Sinai Health System, when Mount Sinai merged with Continuum. And I stayed in that role till November of 2023.

Stephen Calabria: What did you observe specifically in your work with geriatrics patients? What lessons did you take?

Jeremy Boal: Oh, endless, particularly those first 10 years when I was spending most of my clinical time doing home visits. I felt like I gained a tremendous amount of insight [00:02:00] into the nature of suffering.

And the role of society and family and income status and health literacy and all these things that we now call the social determinants of health and the role that they play in helping somebody age successfully or not.

I learned a lot about, I think, what are some keys to happiness in life. Because again, I took care of people who were incredibly ill who by all rights, could have been miserable. And in some cases they were, but in other cases they were doing just fine emotionally.

And I learned a lot from that as well. So the lessons were endless and I carried them with me throughout the rest of my career, as I went into other roles where I had even a wider impact on helping to create a patient friendly, safe, and equitable health system.

Stephen Calabria: You mentioned aging successfully. How would you define that? That could mean any number of things, that you never get sick.

Jeremy Boal: Yeah, there's a lot of potential definitions for that. [00:03:00] So when I think about aging successfully, I think about there's the physical component, which is, what are the things that our genes and our behaviors lead to in terms of our physical wellbeing and the challenges we may face or not?

But I would say an even greater component of successful aging is the mental game. How we relate to what are inevitable changes that will occur to our ability to do what we're used to doing or what we like to do.

It is a fact that everybody gets sick and everybody dies. Healthcare hasn't solved that yet. So how we relate to those things is, I think, really the big question. And something that I've been thinking about and working on for a very long time.

Stephen Calabria: Especially in those first 10 years, how did people generally relate to those things and prepare, especially for their own passing?

Jeremy Boal: I would say, like so many things, it was a bell [00:04:00] curve of responses. We had folks at one extreme end who were grateful for the lives that they lived and were really at peace with whatever was occurring to them and that they were having to deal with even in some cases of extraordinary physical challenges.

And then at the other extreme end were people who were desperately grasping to life and angry and miserable at what was being taken from them and that anger and that misery and that existential dread was so palpable, not just for

them, but also for the people who loved them. And then in between you have a whole spectrum.

Stephen Calabria: So then fast forward a few years and you received a troubling diagnosis. Is that right?

Jeremy Boal: That's correct. In November in August of '23, I developed some symptoms in one of my legs. By September, so a month later, I was told that I probably had ALS, also known as Lou Gehrig's disease. [00:05:00] And by November it was confirmed.

And ALS's just like when Lou Gehrig had it all those years ago, it's universally fatal. Most people die within two to five years of diagnosis.

And the clinical course typically includes and when I say typically, in nearly all cases, total body paralysis, the eventual loss of the ability to speak and to swallow, and ultimately to breathe.

And so it's not a disease where you go quietly. It's a very tough road prior to death.

Stephen Calabria: How did you react after receiving a diagnosis like that? What goes through your mind?

Jeremy Boal: Great question. Having cared for people with late stage ALS and having borne witness to an extraordinary degree of suffering that they experienced many of them experienced. Not all, and then their family members experienced.

I went into a profound depression. I had something akin to PTSD, I was just filled with panic. A sense of [00:06:00] panic and dread, imagining myself in that situation where I can't communicate my needs, where I can't move, where I've lost all my ability, all my agency, and I'm physically in pain and I can't express my need for.

Pain relief and I'm suffering, and I'm watching my family watch me suffer terribly. And it took a while for me to gain a measure of equanimity. I did. Ultimately, I did. And I got back to a place where I feel a tremendous sense of gratitude and joy 95% of the time.

But I would say those first six months were very hard. And it took everything, every tool in the toolbox, to get me back on the straight and narrow.

Stephen Calabria: Which included what?

Jeremy Boal: So it included psychiatric support and psychiatric medications. It included regular therapy sessions. I have had a meditation practice for over 10 years and along with the meditation practice, a lot of study of Buddhism and Buddhist [00:07:00] philosophy.

And so I leaned heavily into that as well. I would say the love and support of family and friends were a huge part of it. And then really learning to see the world through a different set of eyes and gaining an appreciation for all the incredible gifts that this life has granted me.

And focusing on those things, including the ones I currently have, rather than on the things that I'm losing or will lose.

Stephen Calabria: What does ALS treatment generally entail and what is the state of ALS treatment and research?

Jeremy Boal: So in terms of treatment, there's very little that the medical establishment has to offer people with ALS in terms of slowing progression or halting it or reversing it.

There are a couple of FDA approved medications. Neither of one of them has been proven to extend survival by very much, but if they started early in the course, it appears that they slow progression to a modest [00:08:00] degree.

There is a gene therapy for, there's about 10% of people with ALS have a genetic cause. The rest of us, the 90%, are what are called sporadic. There's no family history. There's no obvious gene that's causing it, but for 1% of people with ALS people with something called an SOD one mutation, there actually is a gene therapy.

That appears to potentially halt progression and may even reverse it. So for the rest of us, for the 99% that don't have SOD one, there's very little that the medical establishment has to offer in terms of changing the course of the illness.

Stephen Calabria: Did your medical background make the diagnosis easier to process, or in some ways harder?

Jeremy Boal: I would say early on it made it much harder, primarily because I had cared for many people with ALS in their homes who were in late stages.

And that was very hard to grasp and reconcile a lot of folks who are given the diagnosis of ALS.

They don't have that kind of granular feel for what it [00:09:00] is gonna look like and feel like. And I did. But I think ultimately it was very helpful, because I've had 30 years to think about what I would want if I had a diagnosis like ALS.

And there's no debate, internal debate about where I think the benefits of living don't outweigh the burdens of the degree of paralysis and loss of speech and swallowing and those kinds of things.

Relatively early on, I already it was very clear to me that, I was going to pursue medical aid and dying at the right time. I wasn't gonna put myself through the very late stages of ALS.

And knowing that I had access to medical aid and dying gave me a tremendous degree of comfort and a sense of agency and that continues to be incredibly helpful.

Stephen Calabria: You've written that intellectual awareness of death and the emotional reality of facing it yourself are very [00:10:00] different. Could you expand on that and what the gap felt like in your own experience?

Jeremy Boal: You bet. As somebody who cared for over a decade, cared for people in their homes, with their families with terminal illnesses, in the vast majority of cases, we were able to help people die in their own homes.

You would think if anybody would be prepared to get a serious diagnosis, it would be me. But what I found was that on an intellectual level, I had gained a lot of in insight into what patients go through and their family members go through.

There was a whole much, much deeper, much more granular level of awareness that I gained beco being somebody with a terminal illness.

And I would say the biggest lesson that I learned on an intuitive level, not just on an intellectual level, was that the feeling of loss of control and being in a situation where the [00:11:00] disease essentially dictates the terms of your surrender, without any ability to have control over those things, causes a massive amount of suffering long before somebody reaches the late stage of their illness.

And as I've learned, and as I've spoken with many people since I got my diagnosis who are terminally ill and have serious diagnoses, that is terrifying to them. It could be 2, 3, 4 years off, but they know they have something that's incurable and they don't have a sense that they have any control whatsoever over how things play out.

So that's another reason why I got really invested in trying to help pass medical aid and dying in New York State, because even though the vast majority of people with serious illness will never use it, just knowing it's available is as therapeutic as almost anything else somebody can offer us.

Stephen Calabria: How would you say the diagnosis altered your view of your life's work and of medicine [00:12:00] generally?

Jeremy Boal: In terms of my life work, my life's work I feel very lucky that for the bulk of my career, I always felt that I was in a position to do meaningful and impactful work and make a difference and to do it with colleagues who I love and respect.

And so I don't have any regrets whatsoever about the choices that I made in terms of how I spent my time career-wise. I think that would be a whole other layer of suffering on top of everything else.

If I had made different choices and a lot of it was luck, it wasn't just the choices I made, but I feel like I landed in some positions where I could really offer some help.

In terms of the medical profession writ large, I do think that the palliative care movement, they have done an a tremendous job in sensitizing clinicians and healthcare providers and support staff to the burden of suffering [00:13:00] that people experience when they're dealing with serious illness and giving them tools to alleviate much of that suffering.

And I'm so grateful for that. I think the palliative care movement, the hospice movement in America, they've moved mountains.

At the same time, I still think there's a massive chasm between what we know and what we're capable of doing and what people need.

And there's so much opportunity to close that gap.

Stephen Calabria: During your career, you were also responsible for developing something called the Just Culture framework, which was meant to change the way we think about human error and accountability in medicine.

Could you walk us through that briefly, and how your diagnosis later informed that further for you?

Jeremy Boal: You bet. So I didn't invent the framework at all. The just culture framework was something that we, when we looked at, how do you drive whole system change? So we have these huge organizations, Mount Sinai's a good [00:14:00] example. Many hospitals, hundreds of ambulatory sites, tens of thousands of people who work for the system.

And a lot of embedded culture and a lot of the embedded culture in healthcare in general until recently was a pretty punitive culture. Not, I'm not referring specifically to Mount Sinai, but across the board, in the United States.

When physicians, nurses, staff would make errors, would make mistakes frequently, they were punished for those mistakes. And what we knew from the science of safety was that. Humans make mistakes because they're human.

It's not because they're lazy or uncaring. It's that we're imperfect. And it has to do with the way our brains process information, the way we move conscious activity into subconscious activity.

So there's a whole science behind this and we felt it was really important to start to evolve our culture such that we had a [00:15:00] framework for addressing when things go wrong that doesn't automatically assume it's because.

The human that was involved, did there, they need to be punished, they weren't careful enough, that kind of thing, or they didn't care, whatever. And so we adopted something called the just culture framework, which is a way of thinking about these things.

So I'll give you an example. So if somebody makes a mistake, an error, which means that they didn't intend to do it, but it happened. Our job is to, we have two responsibilities in the just culture framework.

When that happens, we need to console them because they're already beating themselves up over having made a mistake. And there's a lot of harm that's caused to clinicians and others, and a lot of burnout because of people feeling, like they need to be perfect.

And then we need to look at, why that happened. What were the circumstances that led to it, and how can we potentially design the system to decrease the likelihood of that error happening?

And also to [00:16:00] create an environment where if those kinds of errors happen, they don't propagate to cause harm to the patient. So for example, let's say a nurse makes a medication error, gives the wrong medication to a patient, what were the circumstances?

What can we learn from that? What was that nurse overburdened with? Too many patients at the time, were the medications poorly labeled so that it was easy to confuse them. What else was going on in those circumstances?

What did we do or not do to create an environment where that error was less likely to happen? And then to design a system that prevents that kind of error, you can bring in things like Barco Med Administration so that it's much harder for an error like that to happen.

And so that's an example of an error. And then, at the other extreme end, when people do things they know that they're increasing the risk to a patient, but they do it anyway. So it's willful. That would be a category in which we might [00:17:00] discipline somebody.

We have to be very clear about the difference between those two things. In the middle is something called Drift. So what Drift is that as people are doing their work. And as inpatient unit staff are doing their work, they will naturally drift away from policy and procedure.

Because of this way that our brains work, the way that we process information and the way that we will sometimes take shortcuts because we're put in a position where we. We have to, it may be production pressure, it may be too many patients.

It may be issues with the medical record not working correctly, it could be anything. So we start to drift, but nobody notices the drift because nothing bad happens. It's you know how many people drive 35 miles an hour in a 25 mile an hour zone?

And 99.999% of the time, nothing bad happens. And so it starts to feel just as [00:18:00] safe as driving 25 and everybody's doing it. And then one day a kid, is playing with the ball and his ball runs out, falls into the street and the kid runs out after it, and you hit that kid because you're going 35 instead of 25.

But that's normative behavior now. So if you punish that one individual for that behavior, it doesn't actually make the system any safer, 'cause everybody's driving 35 miles an hour.

So we have to design systems that look for drift, figure out why it's happening, and address it before the error occurs. So that's the just culture framework.

There's human error. There's willful, disregard for the rules when you know that what you're doing is increasing risk, but you do it anyways.

And then there's the big fat middle where most bad things happen, and they're mostly due to drift. And each of those things needs to be treated differently if you're gonna create a system that's just and safe.

Stephen Calabria: How has your understanding of that framework shifted since you became [00:19:00] sick?

Jeremy Boal: I think it's given me just more validation that's the kind of direction that we need to move in as health systems, more than anything else. Now I'm a patient, I go to up to a health system in Boston for my ALS Care.

And I'm watching from the patient's seat rather than from the administrator's seat. And I'm seeing all these things play out in real time and just recognizing again, that we can do better.

Imagine a system in which every single person in the system feels a hundred percent safe in coming forward and saying, I made a mistake. Imagine what we can learn. If everybody does that and they know they're not gonna get punished for it, all that data we can use to make the system safer.

That's at the root of why we need to create, use a framework where people know, they know with a hundred percent confidence that they can feel safe bringing an issue forward, and they're gonna be thanked for that rather than punished for it.

Stephen Calabria: [00:20:00] How did your diagnosis impact your relationships? I imagine you developed something of a deeper appreciation, especially for your loved ones.

Jeremy Boal: It really did. It's amazing how having an almost like mind just cuts through everything in terms of knowing what does spending meaningful

time look like and who do I wanna spend it with and what do I wanna do when I'm with those people?

Because every minute is precious and the reality of life is that none of us knows when we're gonna go out. It just happens to be a little more visible for me because of my diagnosis. So it's been very clarifying.

I spend a lot of time with people I love and care about and respect and who feel the same about me. That includes friends, it includes work colleagues, and it includes dear family members, and the time that we spend together is really meaningful.

There's nothing left unsaid. When I ultimately do [00:21:00] pass I'm not for a minute gonna wish, oh, I wish I had told that person I love them. I tell them that now. And vice versa. It's had a significant impact on who spend my time with and how I spend my time.

Stephen Calabria: Reflecting on former patients, are there any patients that give you strength in the current situation?

Jeremy Boal: Very much Stephen, it's a wonderful question I have. I carry so many patients with me and I'm grateful for every single one of them, including there are many that give me tremendous strength. People who had incredibly dire situations.

Who woke up grateful every day for what they had. And I, when I'm picture them, smiling, and I walk into their apartment, maybe it's in public housing in Central Harlem, or maybe it's in a fifth floor, a six bedroom palatial estate on the Upper East Side.

But, you walk in and there's like this energy, this warmth, my whole body. I feel it in my whole body. This is what's possible even in the face of terrible [00:22:00] illness. And for people who really suffered, I've learned so much from them as well. And I carry them very closely in my heart too.

Particularly, there were a few patients that I cared for who suffered terribly no matter what we did for them. The art and science of palliative care and hospice care back then, just like today, it can help many people, but there are some people that we don't have answers for.

Some people with certain kinds of aggressive tumors and the like where, we don't have the tools to alleviate their suffering and, for them, they are a big part

of my motivation to make sure that medically and dying is something that's available going forward, because I know that they would've chosen that and it would've spared them a tremendous degree of physical suffering.

Stephen Calabria: How should physicians talk with patients about terminal diagnoses differently than they currently do?

Jeremy Boal: Oh boy, that is a big, that's the biggest and most important question I think from my [00:23:00] standpoint. So picture ALS. So ALS is like the paradigm of a disease, where it's universally fatal and the course is very difficult, as I mentioned earlier.

Despite that, there are still many people with ALS who go to ALS Centers of Excellence for their care, yet nobody at the center engages them in a conversation about what their wishes might be, what the course of the illness will be.

And so they end up showing up at emergency rooms in respiratory failure, just as an example. And the emergency room physicians are asking the family this, what, what did your loved one, what would your loved one want? What did they ask for?

Do they have documents that say they would never wanna be put on a ventilator or they wanna be put on a ventilator? And frequently the family members say, we never talked about it. They never talked about it.

It never came up. And to me, if that's happening in ALS Centers of Excellence, where again, [00:24:00] everybody has a terminal illness, it's certainly the case in other areas in medicine. I think we can do two things at the same time.

And this is something I learned from my palliative care colleagues. I think we have to learn how to relate to patients who have serious and terminal illnesses in a way that helps them hope for the best and prepare for the worst.

Those things are not mutually exclusive, and I think a lot of folks in healthcare still to this day think that if they're helping patients prepare for the worst, they're robbing those patients of being able to hope for the best, and that is absolutely not true.

So that's my hope. My hope is that we get much better at being able to say Centers of Excellence and Cancer Centers and other places where people have

serious disease, heart disease, lung disease, and everything else, we can do these two things in parallel and patients.

We won't be [00:25:00] hurting patients and their families. We won't be robbing them of hope, but we'll be giving them a chance to really express their values so that you know what ultimately happens to them is consistent with what they would want.

Stephen Calabria: If you weren't sick right now, what do you think you'd do differently?

Jeremy Boal: Knowing everything I know, if I woke up all better? Such a wonderful question.

Yeah, it's a great question. I spent most of my career in administrative roles. The last patient I saw as a clinician was in 2007. And after that I was purely in administrative roles.

And coming out of COVID I was pretty burnt out and I was starting to think about, maybe, maybe at some point it might make sense for me to step back from some of these senior roles with tons of responsibility and the like, and I think even more so now I think I would likely focus my energy on what we were just talking [00:26:00] about, which is, really trying to sensitize and educate and evolve the system writ large as much as possible to never to give up on hope, but to do a much better job of helping people.

Really have the full picture when they're dealing with serious illness. There's a lot of nuance that's involved in walking that line. But I think we can alleviate a tremendous amount of suffering. I have dear friends who have illnesses that they will ultimately die from. And I know personally, and I know through them what a difference it can make when the health system is is able to do those two things at the same time.

So I think that's probably where I would focus a lot of my energy at this point.

Stephen Calabria: What does resilience mean to you now compared with before your diagnosis?

Jeremy Boal: Yeah, so resilience before my diagnosis, I think, it meant, being able to bend rather than break in the face [00:27:00] of, difficulty. And I think to a large extent, that's part of it. A bigger part of it for me now is not just being able to bend in the face of adversity.

It's actually being able to thrive in the face of adversity. And I didn't really fully appreciate. How possible that was. So for example, when I got my diagnosis, for a long time, I never imagined that I, not only could I be happy again, but that I could be joyful again, that I could, just look forward to every day.

And I do, and I work at it. It's a full-time job, but it is possible. It's extraordinary what the mind is capable of. When we apply ourselves. So to me, resilience I think is not just about surviving difficulty, it's about thriving in the face of difficulty. And that difficulty is coming for [00:28:00] all of us.

So why not start now? Why not start right now in developing the tools? To be able to do exactly that, because nobody gets out alive, as we all know.

Stephen Calabria: In the event that there is anyone listening who is also terminally sick, what would you say to them?

Jeremy Boal: I'd say, I'm right there with you, in terms of the vulnerability that we feel when we're terminally ill, the sense of loss of what could have been and, I don't wanna minimize or sound pollyannish in any way in recognizing those realities, it is very sad and scary.

And at the same time, I would share my own story, which I, again, I can't say this is the right path for everybody or will work the same for everybody.

But what [00:29:00] I've learned is, through really exceptional, mental health support and the love of family and friends, and in my case, a very extensive meditation practice and the support of really exceptional Buddhist teachers and meditation teachers and others, that there's a path back to equanimity, to, at a minimum, living.

Making peace with our diagnoses, and potentially even finding joy. But I don't wanna minimize even for a second, the experience of other people who are dealing with terminal illnesses and physical suffering and everything else. It's a deeply personal journey for each one of us.

Stephen Calabria: Well, sir, that's it my, for my questions. Was there anything else you wanted to say?

Jeremy Boal: Only thank you. Thank you for giving me this opportunity.

Stephen Calabria: Sir, you have the last word. What is it you hope our audience takes from this interview and [00:30:00] from your life's work?

Jeremy Boal: I think we covered we covered it in the questions you asked and what we talked about. I would just sum up my own feelings is that I just feel incredibly grateful for so much. And one of the things at the top of my list is that I got to work at Mount Sinai for the vast majority of my career with people that I love and respect.

We're unified in a mission to alleviate suffering for individuals and for communities. And I'm so proud to have worked for Mount Sinai for all those years and grateful.

Stephen Calabria: Dr. Jeremy Boal, thank you so much for being on Road to Resilience.

Jeremy Boal: Thank you, Stephen. It's an honor.

Stephen Calabria: Thanks again to Dr. Jeremy Boal for his time and his story. You can support Dr. Boal's deep commitment to improving healthcare for the most vulnerable through the Jeremy H Boal, MD MSH '96 Endowed Fund, and you can find the link in our bio.

That's all for this episode of Road to Resilience. If you enjoyed it, [00:31:00] please rate review and subscribe to our podcast on your favorite podcast platform. Want to get in touch with the show or suggest an idea for a future episode? Email us at podcasts@mountsinai.org.

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Road to Resilience is a production of the Mount Sinai Health System. It's produced by me, Stephen Calabria, and our Executive Producer Lucia Lee.

From all of us here in Mount Sinai, thanks for listening and we'll catch you next time.