Fixing Healthcare Podcast Transcript
Interview with Alison Hadden

Jeremy Corr: Hello, and welcome to the Fixing Healthcare podcast. I am one of your hosts, Jeremy Corr. I'm also the host of the popular New Books in Medicine podcast and CEO of Executive Podcast Solutions. With me is Dr. Robert Pearl. For 18 years, Robert was the CEO of The Permanente Medical Group, the nation's largest physician group. He is currently a Forbes contributor, a professor at both the Stanford University School of Medicine and Business, and author of the bestselling book Mistreated: Why We Think We're Getting Good Health Care—and Why We're Usually Wrong. His next book, Uncaring: How the Culture of Medicine Kills Doctors and Patients will be published this spring. Together we host the biweekly podcast Coronavirus: The Truth

Robert Pearl: Hello everyone, and welcome to the seventh episode of season five. This season is focused on the culture of medicine and how it both supports doctors and nurses in providing superb medical care in the most difficult of circumstances, such as during the current coronavirus pandemic but also leads them to inflict harm on themselves and their patients. If you want more information on the culture of healthcare, you can find links to articles and other podcasts on the subject on my website RobertPearlMD.com.

Jeremy Corr: Our guest today is Alison Hadden. She is a lifelong athlete, adventurer, and marketing executive at three different, billion-dollar tech companies who was diagnosed with advanced breast cancer at age 38. Now three years later, she is grappling with a terminal diagnosis after the cancer metastasized to her brain and lungs. Alison's driven to motivate the world through her podcast "No Time to Waste." With her signature blend of wit, insight, and vulnerability, she creates unforgettable interviews with dynamic guests like Chelsea Handler, Lance Armstrong and Katie Couric.

Robert Pearl: Alison, it's wonderful of you to come on the show today, and courageous to be willing to tell your story of your battle with cancer and terminal illness. As you know, this season of Fixing Healthcare focuses on the culture of medicine, both the ways it makes doctors heroes, and its problematic underbelly that could result in patients being ignored, mistreated, and harmed. We've had amazing guests on this season five, but all of them have been doctors, and I believe the voice of the patient needs to be heard. As someone who's gone through so much, you've experienced both medicine's beauty and its warts, and I know listeners will learn so much from you. Why don't you begin by telling us how you first knew you had a medical problem and what your initial medical care experience was like.

Alison Hadden: Sure. And thanks so much for having me, invited me to come on the show. I feel honored to be the first, I guess, patient, right? Nonmedical professional to be invited on the podcast as a guest. And I'm happy to share, as I mentioned, my experience, which is I think a bit unique based on who I am, and also the fact that I have moved and received care in different cities. But I hope whatever I can share today can be helpful to patients and helpful to the medical community as I just, again, have no judgment, just sharing my experience.

Alison Hadden: As I think back, it's been an incredible rollercoaster that began in the fall of 2018 when I was first diagnosed. I had just come back from a run. I was someone who, I was 38 years old at the time, was super fit, athlete my whole life, had, I think, gone out for a eight or 10 mile trail run. And when I came back that day, I just had recognized when I was getting in the shower that there was a lump in my breast and I got on it pretty quickly, assuming it was nothing, but wanting to make sure I did everything I could. I was in a smaller town, I mean, it's all relative, but a town on the Central Coast of California called San Luis Obispo, that's halfway between LA and San Francisco. It took probably a week for me to get an appointment and that was me working hard to try and get the earliest appointment that I could.

Alison Hadden: I think it was probably two weeks between that first mammogram, or I had the first appointment then I think I had another week or two weeks until I was able to get my mammogram scheduled, and then another week to get the biopsy scheduled. I also had no idea what standard timelines were like, that was just what I was offered, and so I took it. And I was diagnosed, probably about a month after initially finding that lump in September of 2018, I was diagnosed with stage three, could have been ... It was somewhere between three and four, but let's just call it stage 3C invasive ductal carcinoma. And we found out that it had spread to my lymph nodes and we would require really aggressive chemo, neoadjuvant therapy. So chemo first, and then surgery, and then radiation, and then oral chemo.

Alison Hadden: So I went through 15 months of treatment, locally getting delivered there in San Luis Obispo, but then getting connected to ... Well, I guess I should stop. The first thing I did when I recognized, or was obviously super fearful after getting diagnosed, that the quality of care that I would receive in that small town. I immediately scheduled a second appointment up at Stanford, and the sort of plan that the oncologist locally in that Central Coast town, it was essentially validated by the doctor that I met with at Stanford, the oncologist, who said that the treatment plan is the same treatment plan that he would recommend. But he did say that it would probably be worthwhile exploring different options for my mastectomy.

Robert Pearl: How were you feeling during this time. I mean, stage three to stage four cancer is significant. I think it's what's called triple negative, which is one of the most resistant type of tumors. What was your psychological state like during this period?

Alison Hadden: Yeah, I was super overwhelmed. The news of this came in as a complete shock. Friends said that I was like the healthiest person they know, didn't drink, smoke, do drugs, appeared very fit. So this was just a huge shock to myself and my family. And the overwhelming sort of tidal wave of appointments and scans, and the second opinions that I talked about, everything that happened in that first really six weeks, was just so much. And I remember thinking, "Gosh, I am so on top of things," I have a bias towards action when I'm anxious, "And I can't imagine someone that was older if they had to navigate my situation, if someone was not tech savvy, or even kind of like fast on their feet, and if someone was living alone and having to navigate all of it by themselves." Because I was, I believe, in a lot of ways not your typical patient.

Alison Hadden: I was a marketing executive in the tech industry. I was used to taking charge and leading, and I was project managing my own cancer treatment, which actually I've recognized is still a really valuable characteristic and something that can only benefit you when you're able to be your own best advocate as a patient. And that's been consistent throughout my story. But as I mentioned, I got that second opinion from Stanford because I was so overwhelmed and wanted to essentially double-check the treatment plan that had put together in San Luis Obispo.

Alison Hadden: The Stanford oncologist told me that there would be no benefit to traveling or commuting up to Stanford for chemo. That once you sort of agree on the plan, chemo gets administered and there's really no difference. That was kind of what I was told. I can tell you though, when I went up to Stanford and went and saw their infusion room and the valet parking and the app, even the technology that Stanford had access to for their patients, I just remember going, "Oh, well, this is very different from what the chemo infusion room in San Luis Obispo, which doesn't have any windows, and is all just 10 chairs in a semicircle staring at each other." And I was used to having to try and get records that required me to physically go into offices, get things printed out, have them basically photocopied. Everything was just hard. And again, I was motivated to take charge of my own treatment. But for so many other people, I just would go, "If I can barely keep up, how the heck can they?" And I thought about that a lot in those early days.

Robert Pearl: Let me ask you, again, this season is about the culture of medicine. And what I'm hearing you say is that the physicians evaluated your care based upon whether you were getting the right medication and the right radiation therapy. And they concluded that it was the same. And I have to assume that was going to be excellent medical care. You also pointed out aspects that you as a consumer noticed, such as the windows and the modern-ness of the infusion areas. One part you haven't talked about though is when you have your doctors asking you about your difficulty scheduling these visits, about the impact upon your life, were these aspects of the doctor-patient relationship that you encountered, or were they brushed aside as relatively insignificant, regardless of where the physicians were located with whom you were interacting?

Alison Hadden: That's a good question. No, in my experience, those questions were not proactively brought up by any of the oncologists that I met with, be it at Stanford or they're in San Luis Obispo. And I agree with kind of what you were just alluding to, that they considered it an apples to apples because how they were measuring patient care was they were saying, "Well, it's the same," in that you were getting this dosage of this medication at this frequency. So there's really no difference, right? And yet as a patient, there was a very different vibe, and for me as a young adult, 38 when I was diagnosed with cancer, it may seem inconsequential to a physician, but the ease of use of the app at Stanford, and being able to potentially book an appointment on the app without having to call or sit on hold for a really long time, or bribe the nurses who did the scheduling with donuts, which is what I would do frequently in San Luis Obispo.

Alison Hadden: The iPads that they would talk about, the private rooms at Stanford, I was like, "What? Like this is ..." And I thought about it. I'm like, "Well, man, maybe that would feel different. Maybe I would be able to meet some other younger people who are my age," because in my infusion center, I was the youngest by 20, 30 years. So yeah, I agree with you that that's how it was being measured, that it was through the lens of the medication, the dosage, the frequency, which is why they said there's no difference in the quality of care that you're going to be receiving locally, at least for chemo and radiation. But I did get connected through a close personal friend to Dana-Farber in Boston. And it was recommended to me that if I was able to get connected with the head oncologist, that I should take advantage of that and travel to Boston to have a formal consult with him so that he could oversee my care, even if I decided to get it locally back in California.

Alison Hadden: That was also sort of a game-changing situation, that I recognized it makes me not kind of your atypical patient as well. But I did fly from California to Boston for consultation at Dana-Farber. That was a very similar experience to what I saw with that second opinion at Stanford, just in terms of the technology, kind of the care and attention that I felt like I received there, which also may have been though because of the personal relationship that I had with people.

Alison Hadden: So I made the decision to have a mastectomy through Brigham and Women's, have Dana-Farber, that team sort of oversee my care and the plan that was being executed back in California. And then I received ... I went through five months of chemo, flew back to Boston for the mastectomy, and then went through, I believe, five weeks of radiation back in California, and then six months of oral pill chemo. And I thought that that was kind of the end of my cancer journey. I was essentially an EED after 15 months, and my partner, we moved to Boulder, Colorado, which is where we had always wanted to be. And Rocky Mountain Cancer Center was just about 10 minutes from the house that we purchased here in Colorado.

Alison Hadden: It's just I feel very well taken care of. I have a tremendous amount of confidence in my medical team that's here in Boulder because I ran into a ton of complications with my cancer metastasizing to the brain, having to get emergency brain surgery when they discovered a lemon sized brain tumor in my frontal lobe last April, so about a year ago. And having brain mets essentially show up in scans every three months and having to get stereotactic and whole brain radiation for the last year. So it's been a bumpy ride. But I do look back and go, "Well, at least I feel confident in my team and I feel really good knowing that the plan is sort of set and I get scans every three months, and we'll see what the next three months brings, and then we'll see if we need to stay the course or change treatments." And that's where I am now.

Robert Pearl: It sounds like a, a rollercoaster ride doesn't even start to explain how difficult it must feel, both physically, psychologically. I mean, the fact that you're an athlete and a long distance runner, I'm sure made it a little easier than if you were the elderly patient undergoing this who was not in great health to start with. But I'm sure to every listener, it's a "nightmare journey", and yet you're still filled with optimism and energy and a positive outlook. And I do want to hear a lot more about that in a couple of minutes. But let me double back to the experience early on. You're a marketing executive, you have a degree in marketing, you understand the customer experience, you've been in three big tech companies, at least two of them involve a tremendous amount of scheduling opportunities using modern technology. How would you compare the culture of medicine relative to its use of technology for the convenience of the patient against what you're used to in the job that you've done now for a couple of decades?

Alison Hadden: Yeah. I would say that for the majority, I would say the tech's probably an afterthought. I don't know if that is due to kind of location. I don't know if it's due to funding in a healthcare system, or at a hospital. But it feels like an afterthought when I see it as directly kind of correlated to younger patients feeling understood and feeling like it's not the library with the Dewey decimal system. It's like they have a digital lookup now. And when you run into the more kind of archaic healthcare systems, I think it's just another barrier.

Alison Hadden: Now, I also think it probably has to do with age, right? And if the average age of a woman who gets diagnosed with breast cancer is 62, if I'm thinking about it as a marketer, if your target audience, the average age is 62, or 65, or 70, is technology going to be like the number one thing that you're going to want to invest in, if there's going to be a barrier to use for a lot of your audience essentially? Probably not. And you're probably going to invest a bit more in maybe staff to man the phones so that they can actually have a conversation with people. And that's just me thinking kind of with my marketer's hat on. So I understand it if that's not where they're going to put their money, that the challenge is, it may not be their target audience today. But if we're finding more and more young people getting diagnosed, we need to address what care looks like to them as well.

Robert Pearl: In the culture of medicine, the book I wrote, "Uncaring: How the Culture of Medicine Kills Doctors & Patients," I point out that there are systemic, financial reasons why doctors might not want to spend the money investing in modern technology. But I also think that it's cultural, that they see a medical piece of equipment, even one that has been shown to not add any clinical value, any better outcomes, and they don't value equipment that they would buy that makes the patient's life more convenient, the ability to schedule a appointment.

After work, when you're home, when you have your calendar, when you can talk to your partner, and the culture, what doctors believe, what they value, the norms they hold to, the things they learned in medical school that they take with them their entire life, says to them the patient's time, the patient's convenience, the patient's comfort with the entire process, just isn't that significant. That's at least my sense in the book.

Robert Pearl: I was trying to find out what you do as a patient, getting care at some really great institutions. And I'm not being critical of them because I think what you're describing is typical. It's what happens 99% of the time. I'm trying to get your sense as a patient encountering that, particularly when you come out of a technology marketing background where you created tools to allow people to schedule workouts that were more convenient for them, why shouldn't doctor's visits or treatments or other plans be just as easy to put into action as you made for people wanting to get into better physical shape.

Alison Hadden: Yeah. No, it's a good point. The thing is, I think about my experience with the COVID vaccine, and in Colorado here, having to navigate the, not my own healthcare system, because it was challenging. My own cancer center didn't have any vaccines to distribute. I basically had to go outside of healthcare systems and had to go through privatized commercial locations, like grocery stores, and pharmacies, and CVS, and Walgreens, and King Soopers. And it was so interesting to go through that experience as a patient, but someone in need of scheduling an appointment and how the parallels are. I just kept thinking, "If we can build the technology for me to be able to search different locations of CVSs here in Colorado in a certain distance, and be able to go through an automated process to determine which appointment slots are available, if any," I was checking five [inaudible] for a potential appointment slot.

Alison Hadden: And it was radically different. King Soopers versus Walgreens versus Sam's Club versus CVS, what their mobile and desktop experience were like to be able to schedule a vaccine appointment, but I kept going. If King's Soopers, like why can't everybody get to the technology level of whomever was the best? How come there's such a disparity here in the ease of use? And if I can schedule a COVID vaccine through a CVS, why can't I use a mobile app to book my labs next week before chemo and be able to change it up until a certain point? Why can't I do that? Well, why do I still need a human scheduler to call me and have us go through ... She looks at the schedule and then we go through it together.

Robert Pearl: Alison, people often think about patients as the combination of mind, body and spirit. I'm interested, doctors in the physician culture said they always put the patient first. Relative to the mind, the body, and the spirit, your experience, do they put each of these three first, or are there other things, maybe things that relate to them, that come ahead?

Alison Hadden: That's a good question. I definitely think the body comes first. In terms of mentally and spiritually, I would say spiritually is something that only recently here in Boulder I've watched my medical team be proactive about. I'm super lucky to be in a healthcare system where palliative care is introduced far earlier than kind of the old school association of palliative care being exclusively end-of-life care. So instead, what they're trying to do is introduce the conversations around, what does a good life mean to you? What are kind of your values? What are the things that are most important to you? What are your spiritual beliefs? What keeps you motivated and brings you joy? Essentially everything that you're talking about with sort of the mental, and emotional, and spiritual component, they address that through this palliative care program that they have here at Boulder Community Health.

Alison Hadden: So I'm super lucky because I have been assigned a palliative care nurse. She just came to my house again yesterday for a check-in and we went through some things, and as my physical needs, but also my mental, spiritual, emotional ones evolve as time goes on and I deteriorate, they're able to provide not just the nursing care at kind of end-of-life or hospice. They're also able to provide grief counseling and supportive care through volunteers like ... I just found out yesterday, the resources that they have available to help address not just the physical, but the mental, emotional, and spiritual, I was blown away. I had no idea, because I really did think that care meant the physical care.

Alison Hadden: Historically in my other experiences, it's been physical. And I even would say though, Boulder and my team here and sort of the culture is not without its own faults, because as recent as a couple of days ago, I was waiting on my three-month scan results, which for my chest scan and my brain scan essentially dictate how treatment's going. If there's new cancer growth, where is it? Where do we need to address new radiation, changing the course of chemo. And it is a high anxiety, I've gotten better, but it's a high anxiety time waiting on those results, because they tell you what's going on and help inform what your prognosis might be and how quickly your death is going to come. And I love my oncologist. I think he's fantastic. But even he, a couple of days ago, had told me, "You're going to get the brain scan on Wednesday. You're going to get the chest scan on Thursday. And then Friday morning, I'll call you with the results."

Alison Hadden: And it's Friday morning and it's 8:00, I set my alarm. It's 9:00, it's 10:00. At 10:00, I was bursting so I left his office a message and basically just said, "Hi, I'm still here waiting nervously, anxiously waiting." And I got a call around noon, or maybe 12:30, and he apologized right away and just said, "Sorry. I had a lot of things going on this morning." And he delivered some good news, which was fantastic and a huge relief. But even in that situation, with an oncologist that I have nothing but great things to say about, the recognition of how every minute ticks by for a patient when you're waiting for your brain MRI or your chest CT, those minutes are an eternity. So when you say, "I'll get back to you in the morning," and you get back to somebody at 12:30 with the results that they were waiting on, that has a huge impact.

Alison Hadden: And I think we've been, as patients, just sort of, and I know your book is sort of centered on this, but it's like we are conditioned to expect that of course, they're going to be late. Of course, they're going to say, "I'll call you at this time," and it's five hours later. Of course, they don't think about how anxiety-inducing those hours were for me a couple of days ago. Of course, that's not their job, they're the doctor, right? And you're challenging that notion and saying, "We need to raise the bar."

Robert Pearl: What's amazing to me is the difference in experience when I tell a patient, "I'll see you in a week," and when I've been the patient, and that means I have seven sleepless nights. That difference in viewpoint. Now, don't get me wrong. You know this well, doctors are very busy, and sometimes they can't get back to you as quickly as they should, but I fear that inside the medical culture, that experience of waiting and that anxiety or that sleeplessness is just not valued enough. And I say that because I do believe, and again, your technology background to me is so powerful that we could come up with a solution that wouldn't require time from the physician, that would allow you to have the information you need, or at least a sense of what was going on. And it's just not valued enough to create that. We'd much rather create another big machine that sells for multi-millions of dollars, that as I say, can be advertised, that may not add any value, then figure out how do we solve this problem.

Robert Pearl: I'm sure that if this were a problem in retail, in travel, in some other form of business, it would have been solved a decade ago using technology. And instead, it's basically, from my perspective, ignored certainly for within medicine and to a large extent from outside of it. But let me go back to something you were talking about before, which is your oncologist, has he spoken with you, or any of the oncologist spoke with you, about the end-of-life issues? Or was all this delegated to someone else such as a nurse, or a social worker, or a home health type agency?

Alison Hadden: Yeah, so far everything's been relegated to the nurse practitioner for the initial call that I had going through the Colorado documentation for like advanced directives and the MEET, I think it's called the MEET form. It may be a Colorado state thing. But that was with the nurse practitioner that works directly with my oncologist. And then everything else beyond that, the conversations have been kind of passed along to the palliative care team.

Jeremy Corr: What advice do you have for patients during that seven-day period when they're waiting for the results for a test, or during their first kind of coming to terms with the fact that they have an illness or something of some severity? What kind of coping tips do you have?

Alison Hadden: Yeah, I'm by no means perfect at it, but for me, the worry and anxiety about whatever's in front of you: results, scans that sort of thing, I try and get really grounded in the present, because when I'm able to say, "Okay. Well, is there anything wrong in this moment right now?" I'm usually able to say, "No, this moment's fine." And anything I can do then to just keep myself in the current moment, as opposed to in the fear and anxiety of the future, I'm a huge fan of Headspace.

Alison Hadden: I think it's a fantastically accessible app that has plenty of quick sort of SOS meditations for kind of any paralysis, any anxiety, any feeling of overwhelm. They've got so much in there. It's not just silent meditation, it's guided meditation, it's calming music, it's sleep scapes at night, like bedtime stories that help you wind down. I lean on it a ton, and I did lean on it a ton when I was waiting for the results in the last week, just reminding me to breathe and not get too wrapped up in the fear and anxiety of the things that I don't have control over, and I don't even know what the results are yet.

Robert Pearl: Alison, let me ask you about your tremendous, your wonderful podcast called No Time to Waste. I encourage all of my listeners to listen into your show. You've had amazing guests on it. And in particular, I love the conversation you've had with Rabbi Steve Leder. And one of the things I found that was so interesting to me, because right now I'm writing about the experience that doctors are having in critical care units, taking care of patients with COVID-19, and the experience they have of confronting death continually. I spoke to one doctor who told me he had lost four patients the day before. I talked to another physician who said that she was having trouble falling asleep at night and waking up early in the morning covered with sweat as she thought back to the harrowing day she had had, and the one she was about to have.

Robert Pearl: And you and the Rabbi had an interesting dialogue between this notion of denying death and yielding to its reality. That's at least how I phrase it. Do you remember that conversation? And what was your point of view, as a patient, about how valuable it is to be able to overlook, I'll say a terminal illness or the possibility of death, versus the imperative to be able to see it and embrace it?

Alison Hadden: Yeah. I think I talked about it in the conversation, where I think it's a balance. I'm not great at moderation. I'm not great at balance. I tend to go really hard, or not at all. And with this journey, I hate to say journey, but this adventure, this path that I'm on now, I have no choice but to confront my mortality on a daily basis, but also find a way to not live in such fear of the unknown and the uncertainty around what's it going to look like? When is it going to happen? What's the deterioration going to be? The more I worry about the future, the more I'm taking away from the present. And all I'm trying to do is live for now and maximize my moments in a 24-hour period, which is everything that No Time to Waste is about. It's about confronting that mortality, crafting a life without regrets, and maximizing moments based on the things I talk about, which is gratitude, human connection, and joy.

Alison Hadden: And the conversation I had with Rabbi Leder was basically my fears that, "Well, am I living in denial? Am I not facing the reality of my situation?" And he actually said, "No, you're creating this podcast that forces you to confront your reality every day." And he said, "And if you were to live in that reality 24 hours a day, that's not a way to live." Because all of us could sit around going, "When am I going to die? What's it going to look like? Is it going to be awful? Is it going to be painful? Are people going to be surprised? Is it going to be a long, slow decline?" Right? No one wants to sit around and talk about that or think about that.

Alison Hadden: But that conversation with Rabbi Leder was just so soothing and comforting for me because he's watched and helped shepherd thousands of families through grief and loss, as they've said goodbye to their loved ones. And he just reminded me that no one has ever been scared, no one has ever been panicked at the end. There's always a sense of peace and a sense of calm, and that helps me. I met with the palliative care nurse yesterday who was here mainly to go through kind of a next level of end-of-life decisions and what I want, and really getting into the detail of what do I want it to look like? Where would I want to be? Who would I want to be there? What music would I want on? What about after I'm gone? Do I want a memorial? Do I want to be cremated? Do I want to be ... I mean, all the questions.

Alison Hadden: That to me is almost more important right now than the physical body stuff. I mean, again, I trust my team. I can't control any of that, but I can control broaching the topic of my impending death with my loved ones and having hard conversations now while I'm a 100% mentally here. And I'm just trying to do what I can based on the suggestions of people that I trust.

Robert Pearl: What advice can you offer to doctors and nurses, many of whom listen to this show, about dealing with patients who are confronting terminal illness?

Alison Hadden: So, in my experience, and that's all I can really speak from, it's the loneliness and isolation as a patient, especially a young patient with a terminal diagnosis, or an advanced cancer diagnosis. The loneliness and isolation comes ... It's in the darkness of not speaking about death and dying. That was a really tough period for me. I would say the first year and a half when I was in San Luis Obispo and getting the majority of my treatment there with the mastectomy back in Boston was, I didn't really talk about it. I wanted it to be, at that point it was advanced, it wasn't stage four yet, and I just wanted it to become a battle wound and something that I would talk about in hindsight, in the rear view mirror.

Alison Hadden: And as a result, I wasn't eager to talk about death or dying because in my mind, I was like, "I'm going to beat this thing. And anybody that's going to beat it, it's me. And I'm going to, and we don't have to talk about that because it's going to all turn out okay." And then it didn't. And despite whatever I ate, whatever my physical activity was, how positive my mindset was, the cancer progressed and now here we are.

Alison Hadden: And now, how I feel is if doctors knew that at least, again, from my perspective, that talking about it is actually like the healing. That's a lot of the care. And again, I don't know if that's a doctor's job. I feel, again, like we're so used to that not being part of the physician's playbook, that I don't expect it, but if I were to picture a world in which oncologists or physicians were able to broach that topic with patients and ask them, "Have you thought about this?" Or, "How do you feel when you think about this?" Especially when they're having those very kind of straight up conversations that I think patients really appreciate, even though they're difficult, I'm sure for physicians, but to have that very direct conversation that says, "You now have terminal cancer. Most likely, it is going to be this cancer that kills you. And it's just a matter of time and I can't predict how much time."

Robert Pearl: I suspect that quite a number of the physicians listening in will say they just don't have time for it, or they're not paid to do that. And they're right. But I also suspect, and why I researched and wrote the book Uncaring, is that even if they had the time, that they would prioritize something else ahead of it. Because of the physician culture, you don't really confront death, you find ways to talk around it. And I think sometimes offering hope when what the patient really desires is truth, so that they can make the best plans for themselves, whatever they may be going forward. So let me ask you one last question, and your answers have been so beautiful, I just can't wait to hear what you're going to say to this question. What would be the piece of advice you offer for other women and men facing the same kinds of difficult choices that you now have in your life?

Alison Hadden: In my experience, having the conversations with people that I love about what I wish and what I want at end-of-life, regardless of when that is, it has been difficult in the moment, but afterwards, I feel relieved, because I've done something difficult and that builds self-esteem and confidence. But also I feel like, "Well, at least I've gotten that out there and I've gotten that down on paper. At least they know what my wishes are should something go wrong not on my timeline." And I would encourage everybody, and you talked about Rabbi Leder, he's on his next book right now, that's all going to be about what he mentioned in his recent book, which is called The Beauty of What Remains. And it's all about sort of navigating grief and loss through the lens of not only him as a Rabbi, but now as a son who lost his father after a 10-year battle with Alzheimer's.

Alison Hadden: But he is working right now on what he mentioned in that book, which is how to write an ethical will, which is different from your advanced directive. But this is more about, what are my values and what's my legacy and what do I want the people that love me to carry on after I'm gone. And I told him just a couple of days ago, I was like, "Can you hurry up on the book because I really need the directions to writing that ethical will," because I think I would feel a lot better if I had that documented.

Jeremy Corr: If you could wave a magic wand and make one major change to prevent people from having negative experiences in that situation of terminal illness and kind of coming to terms with terminal illness, and change one thing about the way they are now, what would it be?

Alison Hadden: I think introducing palliative care resources earlier and earlier in the continuum of care. If it really is about addressing the sort of holistic needs of the patient, I see no reason why more patients, even if those not in a terminal situation, if they could get access to a palliative care nurse, or a team, or the kind of support resources, grief counseling, just learning about some of the resources, even as recent as yesterday, it really makes the patient feel seen, and understood, and cared for, that they're not just a number. And especially for those with terminal cancer, there's a sense of ease that comes with knowing that there's an expert who has shepherded so many other people through their end-of-life days. And that eases some of the anxiety, at least that I have around what that period of my life is going to look like. So I would say introducing, if there aren't palliative care resources, introducing those into the sort of treatment model. And if they're already existing, pulling them in earlier because there is a real care that I felt when those services started to get introduced that surprised me.

Robert Pearl: Thanks Alison for being on the show today and for educating the audience on both the challenges of living with a terminal disease and the impact the culture of medicine has had on the medical care you’ve received. You provided a wealth of valuable information for listeners to consider.

Jeremy Corr: Please subscribe to Fixing Healthcare on iTunes or other podcast software. If you liked the show, please rate it five stars and leave a review. Visit our website at fixinghealthcarepodcast.com. Follow us on LinkedIn, Facebook, and Twitter @FixingHCPodcast.

Robert Pearl: We hope you enjoyed this podcast and will tell your friends and colleagues about it. If you want more information on these topics, you can visit my website: RobertPearlMD.com. Together, we can make American healthcare, once again, the best in the world.

Jeremy Corr: Thank you for listening to Fixing Healthcare with Dr. Robert Pearl and Jeremy Corr. Have a great day.