Defying the Odds: Matthew Zachary on Cancer, Advocacy & Patient Empowerment Transcript

(Transcripts are generated by AI and may contain errors)

Introduction to Matthew Zachary

This is the Doctors Making a Difference podcast, living with metastatic cancer, highlighting patients, doctors, and researchers who are fighting to win against cancer.

Today, I am honored to welcome our guest, Matthew Zachary, who goes by MZ. And Mz is here to share his experience. He has been an advocate for cancer patients for many years.

he himself had cancer a long time back and has to be an Advocate help other patients who have dealt with this for a longtime interface for patients and doctors alike.

So I think you're going to find this conversation fascinating. M Z, do you mind introducing yourself to our audience? Yeah. Hello, everyone. My name is Matthew Zachary.

I guess for purposes of context, I was given six months to live with brain cancer. Al, it's senior, 30 years ago, and I'm somehow still here today. Yeah, so that's what it was, was 30 ago and they gave you six month, huh?

Good times, right? Like I said, this podcast are mostly listeners or doctors, since I have cancer myself and get to live that world. Some of the listeners are cancer patients, but it's kind of that interface between doctors and patients alike.

Maybe just start with that journey way back when, like that's devastating. You're a young person, you're studying college, doing all these things, and suddenly you are told six months.

How did you handle that? And obviously you were still here today, so how did not die in six month? Yes, spoiler alert, right? Hi there. Born and raised in New York City, I was a prodigy pianist.

I studied music, composition, film, media, Hollywood, jazz, all through middle school, high school and college. And I would go to grad school to be a film composer.

That was my trajectory in my teens and early 20s and then in the summer of 95, this was again, 30 years ago, I got these weird headaches. I was actually interning at the World Trade Center.

And I thought the headaches were from like the elevators were parabolic, the flux capacitors, like vertigo, whatever it was. You know, you're young and stupid and 21, eh, what have to walk it off, chalk it up.

Got back to college, started to rehearse again. and I noticed I couldn't arpeggiate with my left hand as well as I could. For the non-musicians, arpegiation is like this speed at which your muscle memory can move across the keys.

And so I couldn't play as fast with my left hand as I used to, and I knew right away something was weird. But again, young, dumb, stupid. All right, I'll just switch my hands and play this way.

Literally, that's what happened in the fall of 95. I was able to get as much done as possible, but I'm a lefty, so eventually I could grip my bend.

Early Symptoms and Brain Tumor Diagnosis

My friends signed things for me. The headache got a little worse, But I went to the doctors on campus. Ah, carpal

tunnel. I have a good time. Not blaming cancer, misdiagnosis on campus services, not realizing a closer pianist couldn't play piano well.

There was a corollary back then. I forgive the system for being that, but eventually that fall, the shit really hit the fan. And I started to have slurred speech, blurred vision, fainting spells, this and this nausea.

and eventually after almost five months of being told there's nothing wrong with you, I collapsed. My parents came to collect me. took me home, had an MRI, and then boom, giant tumor in my cerebellum.

Wow. Well, so you had progressive symptoms. Pretty young MRI scan. Even 30 years ago, MRIs were around, but they certainly got better over time. But the MRI scans showed a big cerebular tumor, which, of course, would have caused you ataxia and difficulty with playing the piano.

Actually, pretty incredible just the hindsight comment you made that, oh, I'll just switch my hands and play it the other way. You must have been a heck of a pianist.

I was a prodigy, I really was proud of that. I wasn't Mozart or anything, but I had the skills and I spent 11 years honing them to go wannabe John Williams.

Yes I could just kind of switch my hands, like in that movie Amadeus, he switched his hands. Underneath the piano he would switch his hand. That level of insanity was where I am.

At the end of the day when they finally said you have something in your brain I'm like thank god. It was something, it wasn' crazy. And then it settled in.

That's that thing in my brain. So I had late onset pediatric medulloblastoma, which is because it's congenital. It's a PDT and it normally presents at the age of like eight, mostly in boys.

And mine was like, you know, 12 years delayed for some reason. There's no cog protocol. We don't know what to do with you. Well, we're going to get it out of your head.

Fine. But then the then what was where everything kind of went to pot. Yeah, so what happened? I mean, you're kind of leaving us on edge. You had this crazy diagnosis, this child prodigy, an amazing pianist, and they said, we'll get it out.

And again, obviously, kind a rare finding at your age. So how did it play out? Well, the surgery was gratefully successful. They got out as much as they could with what they called clean enough margins.

Because medulloblastoma is usually very eggy and watery, drips to the CSF, gets in the bone. It's not great. Then they're like, well, let's do radiation.

Why not? So that story is a bit of a comedy of terrors, because I was treated by a neurosurgeon from Sloan Kettering at a different hospital that was in Sloane Kethering.

And then he's like, you've got to go to New York. They're the only ones that'll know how to deal with like an N of one. I wasn't the one kid that wasn' eight in the world.

So I had 5940 CG cranny spinal with a 1300 CG Toma therapy, stereotactic radio surgery, boost to the posterior fossa and the pons. That's something medical.

It's like another language, huh? Right. I could speak that because it's renting space in my head for 30 years. If that made any medical sense, that's what they did.

The three dimensional shit was like clinical trial at the time. So you ever go to the airport and you see the little crystals with your family etched in them in three dimensions?

Like that's the shit they did to me. In the 90s, that now airport tourism stuff. So that was that. They were done, sort of. I had to cancel my grad school plans.

Binghamton, I went to Bingamton of the state of New York, was very kind. they didn't want to be like the college that said to cancer kids, you can't graduate.

so they do the right thing, but I have no future. And then I got back from school, I could play again, not nearly as well as I couldn't beforehand because I spent months not using it.

I was going to ask you that. How did that affect your performance? Because cerebellar surgery, cerebular injuries are hard to recover from. It took me five years.

to kind of get back to where I was. But by then I already was living plan B and I couldn't be a pianist anymore. Within the first three months of post-surgical, yeah, I could sit down and play again, but I would never be at the same pedigree as I am at 11 years of core training, muscle memory and whatnot.

All the neurodegenerative stuff that had affected for months had completely corrupted that skill. So that was that. My dream was crushed. I'm making light of it now, like the worst day of my life.

That's huge. Horrible. Yeah. You know, and I think maybe those who are listening, again, a lot of doctors listening that delivered the cancer diagnosis, or if you're a patient, you know like me or like you.

You get that diagnosis, and it's like the worst day. It's a really rough thing. Maybe we can come back to that, but how do you deliver that news and how you walk with somebody?

Because you can't make it better necessarily, other than saying, we're going to help you through it. You have to say, We're gonna take these steps together.

But it is a big deal when you get told that and you're not sure what comes next. How long you are going live, much less your capability thereafter. you went through all that stuff.

Well, I'll date myself because I had the scan at the MRI center on like December 27th, 95, and then, you know, back then we went out to lunch, my mom and I, we were at home and the machine was blinking in the bedroom.

We only had one machine and two phones in a house back in 90s. I say the machines blinking because who's calling at 3 o'clock on a weekday? So, sure enough, hi there, we found something in your brain, you gotta come back.

So I was basically diagnosed with a brain tumor on an answering machine. But here's where the menschiness comes in, because the neurosurgeon I mentioned was Dr.

Ehud Arbit from Sloan Kettering, and this man was an orthodox Jew who met with us on Shabbos. So my first point of entry into actual clinical that wasn't like my pediatrician for 20 years was an Orthodox Jew who said, I'm going to spend three hours with this family and this kid during Shabbos.

Surgery, Radiation, and Losing His Piano Career

I am not going go to shul, just be there. And he thoughtfully explained everything to us. As much as we were in denial and disbelief, it was so pure and epithetic of this man to take that time on that night to do that.

Regrettably, it was all downhill from there because he set a really high bar for what I was supposed to expect from other doctors. So I got the full panoply of like apathy and empathy along the way.

My pediatric neuro-oncologist was Dr. Jeffrey Allen. He's a pediatric, so he lives and breathes in empathy and parenting, but he never really dealt with like 20 somethings with the same cancer as a two-year riot.

So it's kind of interesting that I didn't seem to get that level of age relevance of support, which is kind like I started the young adult cancer movement 10 years later, not knowing I would be alive 10 year later.

But my doctors at Sloan, because NYU was my care, but Sloans was treatment, it was a hot mess of data sharing and what not, those guys I forgive the 90s.

Could have used a boost of empathy at that point in time. And to the credit, like, these are luminary men. This is like Brian Davis in Mayo Clinic and Tom Byrd in St.

Jude now. So I had these guys in like their late 20s as my pediatric neuroradiation oncologists. It never really felt like they were terribly concerned about who I was as a person, really concerned with data.

But the story that matters most to everyone listening, doctors, patients, whoever it is, just this notion of empathy. And not everyone's bored with it.

Empathy could be congenital, it could learn, inculcated in some way. But this is the one story from 30 years ago that matters most to 2025 and beyond.

and this is what I call the Uncle Jay story. So after radiation's done, surgery's gone, I graduated, couldn't go to grad school. They call us back and say, we would like to give you chemotherapy.

I think I just turned 22, it was end of May, 96. And we said, what the hell is chemotherapy? They didn't explain what that was. Those are not words that you would have in parlance.

Deborah Winger died in terms of endearment. And that's all we know about chemotherapy. Shirley MacLaine threw a shit fit in the hospital as chemotherapy and pain.

That's what we knew. Here's where the karma comes in. My dad's best friend, my uncle, My Godfather, Jay Tishfield, he's currently Rutgers, is one of the smartest men in the world in genetics.

He pioneered nearly everything in 70s that we take for granted today. And he stepped in and he said to these doctors, like, I want to know what chemotherapy you're going to give to Matt.

Can you imagine the gall of this random uncle of his kids saying, you gotta tell me this stuff? No one did that back then, but he called in, he like red-dawned the paratroopers in from all over the world and said, are you gonna tell what this cocktail's gonna be?

And he found out the following, which they didn't tell us. It was the usual, cisplatin, carboplatin, vincristin and cyclophosphamide, those four things.

I know those now because I now those know. But we didn' know what that meant and what they did or if they had side effects. So Jay found out that the percentages of incristian and cisplatin would have guaranteed me being deaf and ruining my neuropathy for the rest of my life.

I was a concert pianist. If I had any chance of regaining the one thing that cancer took away that was the only thing matter to me at 22 was I want to be a pianists again one day.

And these guys were like, what's going to wipe out any chances of you ever having a piano career to extend your life by X? So Jay comes to me, like put yourself in the 49 year old man telling his 22 year-old godson, you'd rather die in five years, because I said 50% chance for five year with no chemo.

Versus whatever would be with the chemop. You'd better die five-years with one thing you could possibly reclaim than live the rest of your life deaf with fingers to play piano.

Like a moment of silence for that. How do you make that decision? And I just said, like, what the fuck? We walked

out. We went back there, had this consult, and I said to them, I'd rather die in five years than have your crappy chemo make me deaf and not play again.

They're great men today. You know, if you're in your late 20s, early 30s. Learn some empathy. But they yelled at me. How dare you defy us? we're trying to save your life.

I really should have just done like the double this, but I didn't, we just said thanks, but no thanks. We walked out and that was technically my last day as a cancer patient at Sloan Kettering.

I was obviously followed up every hour for the next decade. But here I am 30 years later, I can still play piano. My daughter plays piano, or I could still give a concert and I still hear.

Better problems to have, I suppose, by defining the odds. I don't recommend patients declining chemotherapy in today's climate. The science is very different.

But I do want to make a point that what is most important to the patient may not only be what's most It makes sense. I guess that's one of the things, a couple of points on what you just said.

Number one, you made a comment, well, I might date myself. Isn't that a blessing? Think about that. You were thinking on one year, maybe five years at that time, and here we are 30 years later and you're going strong, which is awesome.

And then the second point, like you said, recommend for people to routinely decline treatments recommended by their doctors. But the technology, the science, a lot of things have changed since then.

And I mean, I grew up in the 90s. I kind of feel like as a doctor, this idea of like patriarchal sort of decision made for you versus now it's more like shared decision making what's best for us.

Let's talk and pull on the team. In my training in medicine, we were trained for sure to spend most of our time learning about this stuff, recommending what is the ideal path.

But then you talk to people and say, okay, this works. This is what's been shown, but let's adapt it to your situation. It sounds like you've got a little bit of both, But in that recommendation for the chemotherapy, basically, you were told, my way or the highway, right?

I harp on this only because it's the one true common through thread. No one gets diagnosed on an answering machine anymore, right? This doesn't happen anymore.

There are survivorship programs and care plans and wraparounds and all these things that we fought for for 25, 30 years to have in clinic right now. All these practical issues.

And I was part of that. It was a blessing to be part. I'm still part that, but going back to harp, on that one thing, which is like if they just had the sense to disclose If I didn't have Uncle Jay, I would have done the chemo.

Because I'm blindly listening to I'd rather live maybe another five or six years on top of that five years. Yeah, whatever that number was, it was sure better than dying in five year, even though it's 50% chance.

Chemotherapy Decision and the Importance of Empathy

You're sitting there and want to save my life. How do I not die? I like to not died. I am 22 years old. If they had just taken the time, to explain that there will be side effects to this chemotherapy that directly affect you as a pianist?

Here's your risk. I shouldn't have had to have my Uncle Jay be the person that I didn't know I needed in that moment to help me decide what's best for me.

And yes, we can say shared decision-making these days. I hold it accountable. How is it actually done in practice? Is the first word out of a doctor's mouth, whether it's oncology, rheumatology or whatever it is, what's the most important thing to you besides dying?

Not dying. That's a good question. So I guess that's, you know, your perception of having been in this world in some way or another for 30 years, another 22, 21 year old person that goes in with the same tumor that you had.

What do you think their experience would be today, 2025? Well, fortunately, I had the chance to do something extraordinary, which is create the Young Adult Cancer Movement.

I'm a disciple of Livestrong, so super quick, my 20s were shit, and I didn't really have a 20's. My Plan B just became a day job in the advertising industry.

Fixed computers, did IT, new media, creative stuff. It was fun, because it was pre-internet and whatever, lots of interesting things, Macromedia Flash, PDF, pre Netscape, whatever it is, Dial-Up.

And I got to rehab a little bit and play piano again, but I sense that there was anyone else on the planet that understood what it was to not be 80 and not to be 8 and go through a life-altering experience with cancer.

And it wasn't until I was introduced to the earliest Livestrong pre-yellow wristband world through happenstance of people, which is another story, that I was like, oh my God, where have you people been?

I met tons of other 20-somethings, the 30-some things, who were sick in their teens, 20s and 30s. And it was just like this instant club I hated to belong to, but I thrilled I there.

It was permission to be pissed, what can we do together? It all about, at the time, Gen X. Gen-X and very, very early Gen Y millennials. We were so screwed by the system.

because we got different cancers, we were misdiagnosed, and we weren't treated fairly. We had no equity. There were no standards to navigate us through at an age-appropriate level.

None of that existed. The words adolescent, young, adult, AYA, werent things. They weren´t codes, they weren standards, best practices, guidelines, nothing. I got to be there at the dawn of it.

I gave birth to it, I was the ringleader of the young adult cancer movement. All of this stupid cancer was this nova. to the universe, defining an entire generation's demand to be treated age appropriately.

So long set up to your question, I would like to believe here we are 30 years later, young adult cancer is even more in the news than ever before because of late early onset colon and testicular, it's getting worse and worse, and it is all environment driven and age appropriate is corollary and tantamount to quality of care and quality that if you treat a young adult as a younger adult first and then the disease second, they do better.

They cost less money, that you have less hospitalizations, the more compliant and their quality of life is off the charts, which is good for health economics.

Then go back to work and raise your kids. So I would like to believe today, no one's gonna be given, you of cancer on an answering machine version of walk it off, have fun.

We're not gonna tell you your side effects. Your work, it sounds like it's made a tremendous difference on it. I graduated from residency 2011, but I know that was kind of baked into the training, even at that point, saying, you know, talk to the patient, say what's important to you first, and then you go on and say, here's your options.

Let's talk about what they all mean. It's a lengthy conversation, kind like that first gentleman you came across that spent three hours with your family.

You wish everybody had time, ability, empathy to do that. But it didn't match everybody's experience. And I'm certain it's not perfect now, but I would say that your pioneering efforts and the efforts made by others who have kind of adopted that mindset made a big difference on young adult cancers.

Because you're right, you are not 80 years old. A lot of folks are getting cancer at younger ages. It's increasingly recognized. You look at old death certificates and it is just wasting disease.

unknown. And now we say, oh, they had colon cancer, stomach cancer. They had metastasis to the liver. A lot of things that we just wouldn't have known prior to modern imaging and some of the testing.

So it's just a totally different world than it was even 30 years ago. What have you found in this foundation? You run the Stupid Cancer Foundation. I'm assuming that's still alive and active.

what are the things you were working on with your foundation. Point of order, I stepped down in 2019. New leadership has made it even better than ever.

more money, more staff, or impact. I left the legacy. Allison Silverman, my successor, really a friend of mine, running with it. In fact, I just went to the annual trade show called CancerCon, and I was able to witness what I needed to feel back in 2008 when we gave birth to The Conference.

The entire point of Stupid Cancer as a brand guide was it needed to be like this populist, angry, Gen X driven, we deserve better, permission to pissed, and a way to organize our generation to do something specific.

It was anti-pink anti wristband anti athlete anti fundraiser anti cure anti everything that you would expect from the platitudes of the we can't just presented to our culture.

We had like millions of people I was given like handed to me the world's first live talk radio show for health care. So I'm the first podcaster in healthcare.

May 28, 2007, I gave birth to Stupid Cancer's radio show, which is called The Stupid Cancers Show. And it was live. If you missed it, you're screwed, like the old days, right?

And you had to wait till Friends was on Netflix 30 years later. And between the radio show and the brand and our meetups and launching these trade shows and having road trips and going to Vegas and doing these crazy Gen X things, it just became a populist dream of what it really means to be part of a club you don't want to join, but actuating tangible outcomes in terms of what are these baselines that we deserve as a generation, as an age-relevant group in the data.

It was an absolute honor and a pleasure of a lifetime to give birth to that, to lead it, run it to a worldwide initiative. This AYA program is in Australia and Europe and Dubai and everywhere now.

Like it's a global thing. Baked into an ingredient in a cake now, a person just sitting on the shelf hoping you add some spice later on. Having stepped down six years ago, I've just been witness to it still needs to exist.

Young Adult Cancer Advocacy and Stupid Cancer

And all of the collaborative partners that has 60, 70 nonprofits under the umbrella of Stupid Cancer that are all doing extraordinary work, we shouldn't have to exists, but we do.

I look at it now from a very different light because advocacy is kind of a moving target. Advocacy has to adapt. to the moments, and there will always be a need to welcome people, make them feel less alone, kind of like that direct to patient quality of life service that is just so desperately needed these days.

But there's a larger picture here of what advocacy really could mean down the road, looking in hindsight, like it was, that was important, what could be next?

You know, one of the things I think about on this, and again, I walk on both sides of this because I often am the person delivering the news about cancer and then the very next day I'm the patient receiving treatment for cancer.

It's kind of a terrible juxtaposition of these two roles, but what I wanted to ask you is, as I've thinked about a person today, maybe they really do just have six months.

And maybe they've got 30 years and we just don't know that. What do you think is the right answer to tell somebody when they're coming in? Because I've been there, you've be there.

It's a terrible moment for your life when you say, hey, You got cancer or you got a bad cancer for a young person. I think the disadvantage I have is that I'm not a doctor, but the advantage I had was I was not doctor.

So I can say things like this, no good Hallmark card for dying in six months. How can I support you? What can i do for you or is there anything you need that i can help you with?

But I am in a weird position because if people happen to know me, I' m the Uncle Jay of other people then. If you happen to know me, I can help you do all sorts of stuff because I know how the system is working.

What I cannot do is extend your life. Nothing clinical here. So I look at what's important to you, keep a track record, make a footprint, have a legacy, hug your kids, do what you can with the time you have.

And it's not a cat, oh, we're all going to die someday. Stop saying that, people. Yes, were going die some day. I don't need to be reminded of that when I was just told that I have six months to live.

So yes, I've met people that are end stage of terminal and so many friends have died. It literally piles up in your brain. You have to build a thick skin to it, which is what I admire about oncologists, oncology nurses, and oncologist social workers.

you have build up kind of like a strategic apathy on the inside because you got to sleep at night and watching a kid die one day and then trying to fall asleep at.

I don't think you guys get enough credit for what you had to deal with as just a burden of Hippocrates. So I just want to give a shout out to all the doctors who you've chosen medical school, you have chosen Hippocrates, and you know going in it's going to totally suck sometimes and have to live with that and sleep and hug your kids and be grateful at the same time.

So with just needing to be said, there is no one good thing that can be just said. It's just honesty and the truth is all we expect. You know, another thing, my cancer is really rare.

It's called solitary fibrous tumor. The type of sarcoma, it's about one per million patients, and it was just rare, I found some support on Facebook and some other people that I've encountered, other that have this cancer through that, And I find that to be really beneficial.

But you know depending on what it is, because there's hundreds of types of cancer, What do you tell someone who is newly diagnosed, especially a young person, who says, hey, I feel alone.

I don't know what to do. The doctors are telling me this, but it just doesn't make sense, or I won't speak doctor. There have been a bunch of studies that have shown, once you say the word cancer, people dont hear anything else.

Where do turn people? Where to have them go so they can receive answers, support, and not just from their doctors, from peers and community? The one life hack I tell people to is don´t use AI, always turn on voice memo when you go see your doctor Because you can't absorb it.

The Charlie Brown wah-wah happens. And the second anything goes on, turn your voice memo on your phone, let

it record, deal with it later. You don't need to be as present as you need be.

Just let the care team tell you what their update is for you. Like, where's the circle of trust? Where is this direct to patient quality of life universe?

All these nonprofits that are out there trying to do the right thing to help you, what I would colloquially call make it suck a little less. That was what Stupid Cancer is kind of like tagline was.

We help make and suck it a bit less because it's going to suck, but at least have it be less terrible with us. If you know someone like me, I can tell you here's nine organizations that I think would fit the bill when you're ready for them.

In other words, if you are younger, there are camping retreats, and there excursions, kayaking and adventure retreat, workshops, seminars, webinars, conferences, trade shows, meetups.

tons of stuff that can give you some degree, again, not for everyone, it's the ones that are ready to welcome it that's valuable to them. You don't want to shove this down people's throats.

But here's Oz. Oz you didn't really want. It's going black and white instead of color, but here is the Oz of all these things that you could choose to take advantage of.

The challenge of that is none of it is really indexable on search or AI. That's a whole other podcast about some of the pitfalls of being a non-profit organization that's struggling or maybe under two, three million dollars.

No one knows you exist because they weren't looking for you. You know, no one goes to cancer college to get sick and know what to do five years later.

I'm sure you didn't. You were at the med school, not cancer school. So, from that perspective, it's going to be really hard to know… what could be out there for you.

Like me, I mean, that was the 90s, but I spent seven years alone. And I happened to stumble into something, which is why I wanted to create the largest brand in the world for Gen X, and younger adult cancer.

Now it is pretty discoverable because it was a great brand. But hopefully, the cancer center you're being treated at, rural or otherwise, should have a basic oncologic familiarity with AYA.

And if that is the case, they should to have some basic familiarity that are extramural of the clinic, whether it's a support group here, or whether there's an nonprofit here.

Or if you're employed, there is like a cancer in careers. If you need lawyers, this triage cancer. Again, these are not groups you are going to normally think to look for.

but there is a huge ecosystem that was born of this nebula in the early 2000s for young adults with cancer. And again, for the older folks that are out there, I mean, even like ARP has cancer support groups, they've even bought into that too.

It should be a lot easier today to find communities that were there for you, that you can trust. But that might not be true for, you know, everybody's a Belgar.

For socioeconomically different communities, for people of color, it's going to be very different. I'll button it up with, like, in terms of certain ethnicities, cancer isn't discussed in the Asian community, the Hispanic community.

You don't talk about cancer. And then I meet a lot of young adults that are of Hispanic or Asian-American heritage. And they have nowhere to talk to. They never met anyone of Asian American or Hispanic, even Inuit Native American heritage, where they can talk them.

Because the parents are like, we don't talk about this. It's the spirits, whatever it is. There's real data. on what that means to suppress your capacity and willingness to look for resources because you just feel that no one's going to really understand you.

We used to just kind of die 30 years ago, so these are all, like you said, better problems to have, but the fact that we're so aware of them now means it can only get better.

Yeah. Well, it's nice to know there are resources because nobody plans to have cancer. Like you pointed out, you're thrust into this club that nobody wants to be a part of.

And it is not like you went to cancer school. Nobody did. We have our oncologists, our cancer centers that have a lot of resources accumulated. But if you are a patient or you have patient family member, that's not what you planned on it.

You have suddenly Cancer X, and then you're hunting for resources, which, you know, your physician can provide a lot of resources. The Cancer Center you see, I mean, all that team can provided, but there's a lotta community support and foundations and networks.

Supporting Newly Diagnosed Patients

And there are some out there that are probably hocus pocus, that are really just focused on advocacy, getting information, answering questions. I'm thankful that stuff has been developed.

Personally, I am thankful for it. And I think for on behalf of my patients. Sometimes you say like, well, you've got this. But in our 20 minute, 40 minute office visit, it can't possibly answer all the questions you have.

As soon as you go home, we're going to have another one. So having a colleague or a peer who said, hey, that's kind of like what I've gone through. You can even state a value on how much that means to people.

Peter can I ask you a question? You bet. Could you point to one or two specific things that have changed your practice behavior now that you are on the other side of it?

I don't know. I think I was pretty compassionate. It's a little bit, I just know inside, it feels different because I've had several patients I have diagnosed with cancer since my diagnosis a couple of years ago to come to somebody and say, hey, this is rough.

You want to talk about it? Or let's talk in detail. And I even more tuned in, like what you said, instead of just saying, well, here's your cancer, and here is your prognosis.

a little bit more tuned into the idea that what matters to you, what comes next, and what are the important things you want to accomplish in your life.

Let's see what we can do. Because sometimes, before I'm sure I was guilty, everybody is like, well, you need to stay in the hospital longer. You need do these treatments longer, but sometimes you have to sit down with somebody and say, Well, What's most important to?

And they say like well most import. for me to do X, Y, or Z, and it's not me being in the hospital. So having those conversations a little bit more frankly, I don't know if it means anything to patients, but it hits pretty close to home when we have those conversation.

It's hard to quantify because you're in middle of it so much. Only as you gain perspective by looking in hindsight, do you realize the changes that have occurred.

Yeah. Thank you for answering that. Just the very idea that the question, what's most important to you, is asked more than it used to, just helps me sleep at night more.

Yeah, nobody likes to talk about hospice, but I feel like that's been a blessing just in the time of my career. Hospice was a thing when I graduated from residency, But I think now more of our hospices agencies are saying, hey, we're here to help for the person who says, I don't really want to go through all the tremendous chemotherapy or things that are going to make me feel terrible.

It's really important for me to be at home and go out and do the stuff. my family and be there. For some people, that is such a blessing for them because before them, contra was always, you stay on your treatment, stay in your, treatment you, stand your treat no matter what.

And now, especially with people that are maybe a little bit more senior, a lot of times hospice, they'll choose it a bit sooner because they will say, well, the treatment makes me feel terrible and for a very small additional amount of time.

I feel like a lot of people choose hospice sooner rather than having to be home from hospital and they're dying in two days. They're on hospices for months and months, and it provides them a lotta support and gives them lot a resources that they have at their house.

What are your comments on that? That's better problems to have. This shows that the empathy of respecting a patient's wishes, as long as it is a completely objective, personalized shared decision, give them what they want on the terms that matter most to them, with empathy and do not feel like you're violating Hippocrates by giving them the agency and autonomy, I said that word twice, that matters most to them.

It's kind of hard sometimes on the doctor's side because a lot of patients, you know, have really adopted the idea of shared decision-making, which I really like, and I think people are happier with the decisions they make when they go through that.

Sometimes, though, when you get to the back side, I'm like well, well I'll take what you say into consideration, but, the internet tells me yada, yadda, or AI tells this, my uncle Billy's great aunt told me that I need to do this.

And sometimes you have to say like, well, you're welcome to seek any opinion, any consultation you want. But I've got to tell you, got be really careful with that because sometimes those decisions are going to really not only affect the length of your life, but the quality of what I would hope for.

Most of my patient interactions is that there's a level of trust where it's open and transparent and you can honestly talk about it. And it is both ways.

I trust the patient and they trust me and we make a decision together and feel good about because you know that you discussed the options and the person got the thing that they wanted to get.

Well, again, that word trust is so user-defined these days because of confirmation bias and the internet is like 4% good and 96% terrible. So I'm sure you experienced pre-imposed your diagnosis, your patients are like, well, I saw the drunken neuro piss in a cowbell after being warmed up in the copper pot on a Sunday cures cancer.

Like, really? Okay, great. You go enjoy yourself. Go do that. And there really is so much being done on cancer research and development.

Shared Decision-Making, Hospice, and Trust

I mean, it's tremendous. We're in an age where there's just groundbreaking research, and amazing stuff. And so what was true 20 years ago for somebody's relative is probably not true now.

There's lots and lots of things that can be done to change the direction on cancers. Lots of cancers, when we say cure cancer, we're really talking about hundreds, if not thousands of diseases.

their treatments are a little bit different. But the more we understand it, the More we parse it into little bite-sized

pieces, The more, we can come up with treatments that actually work.

If you have to have cancer, it's better to get it in 2025 than it was in 1995, I would say. Would Deborah Weir have died in 2025 is the question, right?

They have reboot that movie for 2025, see if he died. You know, and I hope that 30 years from now, It's Better Still, by far. I Hope it leaps and bounds better than even is today.

Well, MC, tell me what comes next for you. You're obviously a pioneer in this space, you've influenced lots and lots of people with your advocacy, and you're still going.

And you divide the odds. So what's next, for MC? Well, I'm still on the air, 18 years later, my show Out of Patience. So the stupid cancer show became Out Of Patients after I stepped down.

And I've been on air pretty consistently, 2,000 episodes in total so far. Well next time you're in New York, literally you. Oh yeah. Open invite to come here.

I appreciate that. We'll do a guest swap. My show is pretty much my anchor, what I am known for. A ton of listeners and I do lot of B2B work with my shows to amplify messages and reach specific audiences and do lots of conference reviews on my like a mini board center, cancer center.

What do you call it? I'm writing a book. called We the Patients, pub date is June 3rd from Wiley. That's gonna be really exciting. It's a semi-history of healthcare in America with a mini biopic, some information about how I got the auto cancer movement started, what advocacy means, and kind of like how we moved it to a hellscape of health insurance destruction of this country, leading up to the murder of that healthcare guy.

And what I think Americans can start to do for the first time, we have to redefine advocacy for patients. And then following that up, I'm launching a new movement, my next stupid cancer I could tell everyone watching and listening here, also called We the Patients.

It is America's first cancer patient rights lobby. And we are going to be turning 35 million Americans into the first Cancer Pack.

Out of Patients and We the Patients

Every every mob in this country is organized in some small way to fight back against legislative bullshit. Why haven't we? And with prior off and delayed deny and financial bankruptcy, at the tip of the spear, every diagnosis, we need someone to protect us from that.

So we're calling for something called the Cancer Patient Protection Act for 2028. And we'll be electioneering and doing district work to figure out what that really means to guarantee a navigator when you're diagnosed that isn't part of this system, but whose sole job is to serve as a public defender to project your doctors from moral injury by making their life easier, by make sure the patient has navigation through Prior off, delayed deny tactics, insurance and billing issues, predatory billing, and financial bankruptcy.

Those are the most important things. And in doing so, yes, I'm on the side of moral injury. I work with a lot of doctors who have colleagues committing suicide.

It's the worst thing ever. The undiscussed or under discussed other side, of how destroyed our culture has allowed the healthcare industry to become. We the Patients is going to be America's first cancer patients rights movement and it is all about protecting doctors, nurses, social workers, the entire system and of course the patients and their families for me are ruined because some health insurance company thinks that their doctor knows better than yours.

Well, I can't wait to see where it goes. I really appreciate you taking the time to join us today. Hope people will

check out your book, your podcast, you work, and your movement.

You've done tons of stuff and I hope you'll just keep it up. Thank you so much for taking Now, Peter, this has been an absolute pleasure. I really appreciate the opportunity.

Thank you. Thanks for tuning into the Doctors Making a Difference podcast. And thank you for what you do to help your patients and your community. Your work truly helps so many people.

We produce this content to you have the tools you need to stay in medicine and to highlight the amazing work being done by physicians around the world.

Please note that while I am a physician and many of the guests on this program are also physicians or other professionals, the discussions on the podcast do not represent my employer or any professional organizations to which I belong.

This podcast is for your information and entertainment only, and should not be taken as professional advice. You should seek appropriate professional advise pertaining to your own situation.

Please check out more of our content on our website, DoctorsMakingADifference.com. Also, please follow, like, or subscribe on your podcast player or YouTube channel, and give us a five-star rating.

It really helps to spread the message. Finally, if you'd like to be a guest on the podcast, Or if would like nominate someone else to a be guest, Please visit the website or email admin at Doctors Making A Difference dot com.

See you next time.