

Kevin Stranberg

Marsha Hystead: So I'm super excited to present Kevin. He is director of strategy and patient experience. He's the president of Stranberg and Associates, his consulting group, and a senior consultant with the Baird Group. He's done lots of speaking at conferences and sharing his insight around improving the experience that patients have with health care.

So give a warm welcome to Kevin.

Kevin Stranberg: So a few years ago, I was on a plane heading from Minneapolis to San Diego. I was seated in seat 34B, last row, middle seat. Right next to the bathroom. You've been there, right? Yeah. Well, magically I was upgraded to 1A. Again, never happens, never happens to me, but it did. So I got all my stuff and I was walking up to 1A.

And, there was a woman sitting in 1B. Let me describe her to you. Her hat matched her belt, matched her shoes, matched her briefcase, matched her iPad cover. You can see her, right? In fact, some of you want to be her. Maybe even a couple of you want to do her. I'm just saying what I know is, there are probably some of you who wouldn't want to be anything like her.

From that description, you already know her, right?

So I squeezed into 1A and what I didn't know is that in first class you get the whole can of soda and you get a *glass* glass with ice in it. So we took off, I got my soda, I was so excited about it, and I opened up the can and it exploded. I mean everywhere. There were flight attendants with towels, wiping the floor, wiping off 1B, wiping off the ceiling. Literally.

1B said nothing. Two and a half hour flight. She said nothing. So we get to San Diego and I'm feeling like, Oh, my first first-class experience, this is horrible. So we get ready and she's getting her stuff, she's getting her iPad, she's getting her briefcase, she's getting ready to go, and she leaned into me and she said nine words. The whole trip, nine words.

Did you know it was?—"I hope the rest of your day goes better."

You know, people surprise us all the time. We have moments of encounters that happen, to each of us. And there are moments of time where we have a sense of humanity that feels differently because of the encounter, right?

I'm never going to see 1B again. She's never going to see 1A again, but it's about that moment in time that's so important. It really is about those moments. For most of us, those moments are far more important than a can

of pop. Especially in health care. People come to us at their most scared and vulnerable times, and oftentimes in life, the moments are the sad ones.

They're the bad ones. Yes, we have a sprinkling of good along the way as well, but oftentimes they're complicated. The mix of good and bad, or they're just plain bad. That's what I want to talk about, is we talk about the moment that everything changed.

We, of course, know that this conference is called Believe in Better, right? Lots of the information that we got this morning, which I thought was spectacular by the way, was all about better. In fact, the conference book talks about better thinking, better health, better lives, right?

I want you to stop for a minute, back up. Let's talk about believe. Believe is an incredibly important piece of who we are and what we do.

We need to center our work on *believing*. The better will come if we believe.

My niece was killed in a plane crash. Her mom, my sister-in-law, described the experience as looking through life with a screen door. You could see things happening and you could see people having a good time and you could see people going on with their stuff. And she said, first of all, I didn't want to. Second of all, I couldn't see it clearly. And third of all, none of it mattered.

That's the moment in time that I'm talking about when everything changes. Yet what I know from that is we often think that it's the moment when the emergent situation happens. That's when everything changed.

When the accident happened, when the diagnosis happened, when the person passed away. That's what we think is the moment when everything changed.

Here's my challenge for you. The idea of the time when everything changed—the moment in time when it changes—is when we decide, that we have a new future.

That we decide, that our sense of purpose may be different, but it's still valid. The time when we decide to move forward rather than stay stuck because of what's happened to us. That idea is really a personal journey. How do we get there? It depends on the individual. It depends on what resources they have.

Every health care journey is individual. Every health care experience is valid. And as we think about that as caregivers ourselves, we need to process the idea of how do we help people in those situations? How do we bring them along on the journey? How do we get them to the moment of seeing a

future? Because if we don't have that sense of future and we can't help to create that for the people that we take care of, it's really hard to sleep at night. And it's almost impossible to get up in the morning.

The plane crash happened long ago, yet my sister-in-law still talks about the spaces between the screen door have gotten bigger, but they've never disappeared.

They will always be there. We will always be affected by the things that happen to us in our lives. And knowing that, changes how we do our work.

How do we know what that journey looks like? I would say it has to do with first voice. For me, first voice is all about the idea of sincerely and totally listening to your patients, to your health care customers. To the loved ones who are supporting those people who are getting care.

First voice is about not what you're going to say, but what do they have to say? What's their message, what's important to them?

I loved the information this morning that talked about, what do whiteboards talk about, and generally whiteboards talk about the plan for the day and the schedule for the day.

I went into a patient's room—an elderly man, and there was a section on the whiteboard that I loved that said, what's important to me, and patients filled it out—went into this elderly gentleman's room, and he had one word written on his whiteboard. One word. Do you know what it was?—Spot.

They were sneaking his dog in.

How can you think about a care plan without thinking about Spot and how a valuable Spot is to his healing process?

So first voice for me is the idea of stopping. Stop thinking about the care plan. Stop thinking about how you're going to do the next billboard or the next radio ad or the next media blitz and instead back up and actually talk to people about their experiences.

I'll give you a prime example. We talked about HCAHPS this morning, and Dr. Maples I think did a really, really good job of discussing this idea of how does data fit with the real experience? So I'll give you a prime example. At my hospital, we were doing really, really poorly on quietness of the hospital.

Many hospitals have trouble with that. So what do we do. We form a team, right? Get everybody in the room. Let's talk about solutions and all decide that we were going to change every single wheel on every single cart used in

the patient care area. Expensive, yes. Time consuming, yes. Many disgruntled employees who had to change those wheels. yes.

What was the result? Our HCAHPS scores were just as horrible as ever.

So we started talking to patients about it. We went to patients and they told us stories like this one woman who said, when I was in the bed, I was woken up at three in the morning, not by someone taking care of me, but by the noise in the nurses' station. I got to learn a new knitting stitch at three in the morning because one nurse was training somebody else on how to do it.

That's first voice information. That's where we need to start. We don't need to start in what we think the experience should be. We need to start what the patient believes and I absolutely agree with Dr. Maples about this idea of patient centered care, and I would push it one step farther.

I would say we're not done when we get to patient centered care because then we need to go to patient driven care. What is important to them? Not what we believe is important to them, but what is really important to them.

So if we think about this idea of first voice, how would that change our work? Think about your work and how often you have sought the input from direct consumers of the work? How many times do you do that?

We talk about bedside shift report as being the ultimate best practice, right? Here's how bedside shift report often looks. The nurse who's going off duty and all of the staff who are going off duty, talk to the nurse who's coming on duty and the staff who are coming on duty, and there may be introductions. Maybe, maybe not, but rarely do we start with, so Mr. Jones, you've been here for three days. What's important for you today?

That's first voice. That would change our work. It also would change our purpose of the work that we do, because it's no longer about what we think is most important. It's about what patients understand is most important for their healing process.

So this idea of first voice takes us from this realm of telling people what they should be doing, including what's wrong with them, how they should feel, when they're better, when they need to leave. All of those things are putting expectations on them. And I would say to you, we need to change that because what would really happen if we use first voice? All of a sudden, what would you hear? And more than that, what messages would you get from what they're not saying? What is hidden from us in the obvious work that we

do, and how could we find a new health care model that looked at first voice as the primary voice of the work that we do?

It's a difficult shift, I'll give you that. It's not an easy one to understand or embrace. And I would say for many technicians, providers, nurses, it's a little frightening. You don't know what you're going to hear. You don't know what's going to happen next. All of a sudden, what you expected for the day may change drastically depending on what your patient, what your customer, decides should be the driving force of the day.

Now, I'm not saying we should throw all of the care plans out the window. That's not what I'm saying. What I'm saying is let's process this, from the idea that patients have a vested interest in their own health. Rather than appearing at our door, and being told, let's treat them like smart people who want to get better.

And in doing that, it changes the expectations that we put on them, to opportunities for us to make them healthier, which is about life care, not sick care, right? It's the idea that first voice can give us insight into people's psyche and we know how valuable that is for being healthy.

We're going to try an experiment today.

We do have, by a gracious opportunity, to be able to actually try and experiment, we do have a patient here who's willing to give us some information about her road in the health care model. We call it an experiment because honestly, we have no idea what's gonna happen.

I have met Zoey just for a few minutes. She has some interesting information to give us and we're going to show you a video about who she is and then we're going to take some time and I'm going to talk with her a little bit about what I think might be an important discussion about why first voice drives health care rather than the other way around.

So are you willing to play with us? Good. So what I know about Zoey is from a single phone conversation, and this quote came up so strongly in my discussion with her: The strongest among us are the ones who smile through silent pain, who cry behind closed doors and fight battles no one knows about.

I love the phrase be kinder than necessary because everyone is struggling with more than what is evident. Everybody.

I started this presentation with this idea of moments that changed everything. All of us have them, and if we can bring those emotions into our work, we are

better caregivers. We are better at what we do because of it. Don't leave it at the door. Don't forget about it. Don't lock it away. Use it to your advantage, especially in gathering first voice information.

So here's what's going to happen. We're going to show you a video. Thanks to Hailey Sault for creating this video, because I think it really gives you the essence of who Zoey is.

And then Zoey's going to come up, and we're going to see where it goes from there. So, on the video, Zoey Cohen Leege, who has a very interesting story, even previous to any kind of medical situation, and that's where we're going to start. So let's see if we get the video going.

Zoey [speaking in video]: I describe myself as a painter of curiosities. Yeah. I made one for my grandma too, and her only request, she wanted one of Lake Superior and one Caribou Lake and just no weird stuff. I did a little one and it had a woolly mammoth skull in the sand, just 'cause I like woolly mammoths, so I like to put things like that in my paintings. Like: I can do that for you, Grandma. She actually probably would like a mammoth in here.

I came up with the Instagram name for myself: mythropologist. Which I made up and I think that says it all. And people are like, What is that? And I'm like, exactly, what is it? So, it is what you want it to be.

I always have been interested in art, but I don't think I ever thought ... I don't know, I think it was like I was scared to try and sell work or, you know, it was going to get rejected or it was going to be too hard. I think I've only gotten more comfortable with it as I've gotten older.

When I was a kid, I wanted to live in Wales by myself and wander around and paint and herd sheep or something like that.

Just funny 'cause for whatever random reason, in high school I was voted the most likely to go to space, not to be an astronaut, but the most likely to go to space. I think some friends just thought it was funny.

I live here with my husband, Taylor—it was just our third anniversary yesterday—and my two stepdaughters, Phoebe and Chloe. Phoebe is 11 and Chloe is 14.

I am a Telemark skier, which is a traditional type of skiing that comes from Norway.

Also in my non-art life, I work in disability advocacy, have a background in vocational rehab counseling.

I'm a really happy person. I wasn't always a really happy person. I think it took a long time to figure out a good balance. I have a really good sense of humor and a good attitude, and I like to have fun. And make the most of things. So, yeah, I am happy. I don't know what the future is going to bring, but I just kind of go with the flow. That's all I can do right now, absolutely.

Kevin Stranberg: Great. So I'm very proud to introduce Zoey Cohen Leege.

[Working with mic] Yeah. Good luck with this. Yeah. If I could read it then I'd know. I got it. Here we go.

Zoey: I feel tiny in this chair.

Kevin: I know. It's a great big chair, isn't it?

Zoey: My feet don't touch the ground.

Kevin: So, first of all, that's a great video. Tell me a little bit about the day that they shot it and what it felt like and all that.

Zoey: I had a painting started in the basement. And, I had told my husband and my stepdaughters they were coming and they kind of forgot. I think Taylor was actually in the shower, so they did my portion first and I was like, Oh, there's a film crew here. So, and then I got to work on my painting for a while, and the girls were hanging out. Chloe who was 14, was embarrassed and hiding in her room the entire time.

Kevin: "Not pictured." Yes. Got it.

Zoey: Yup. Yup. And Phoebe was like, what? We're in a movie? Okay.

Kevin: How long did it take?

Zoey: I think they were there, they got there fairly early, 'cause I'm a morning person and they were there until around, I don't know, one or two and, yeah. Yeah, just filming and it was a lot of fun.

Kevin: Great. So. Mythologist.

Zoey: Mythropologist.

Kevin: Methro-...

Zoey: Not meth!

Kevin: Not meth- . Okay. Let's back up. Myth-row-pologist.

Zoey: Right.

Kevin: So where did that come from and tell us a little bit about what you mean by that.

Zoey: Well, my undergrad is in art history, an extremely useful degree.

Kevin: Mm-hmm!

Zoey: And then I went back to school later for vocational rehab counseling. And I had kind of pushed art to like, Oh, I'll do that as a hobby, or if someone wants me to make a poster, and ...

Kevin: When you become a hermit in Wales, you can do it.

Zoey: I'll do that when I retire. There's no time. I work. I worked full time for the state for many years as a voc[ational] rehab counselor.

And then I made a career change, a few years ago, and managed a project at the ARC Northland in Duluth, a local disability nonprofit, and decided I was going to take a painting class with a local artist, Adam Swanson. And he was like, Hey, I think you're pretty good at this. You should just keep painting.

And so I did, and decided I should probably start marketing, and I just came up with that name because I like to add things from mythology and anthropology and things into my paintings ... and cryptozoology as well. So ... just sort of went from there and started having art shows ... in addition to working full time.

Kevin: Cool. They're wonderful. So I know your grandmother is here. The big deal about that is, did she hang the paintings?

Zoey: Yeah, she has two paintings in her apartment, one of Lake Superior and one of Caribou Lake where our family cabin was since she was a little girl.

Kevin: And if I asked her if they're always hung, or does she just put them up when you arrive, what will she say?

Zoey: They're really heavy and difficult to hang, so I don't think she's taking them off and on the wall, but I don't know.

Kevin: She may be calling someone—a neighbor—to help her with it.

Zoey: Right. Who knows?

Kevin: That sometimes happens.

Zoey: Right.

Kevin: So we saw the happy, vibrant person who's involved with their family and has a really positive attitude about life, right? And I assume that in the last couple of years that's changed a bit.

Zoey: Yeah. Actually, well, last winter, just this past January, I started having just some sort of strange, like, back pain and things like that. And I didn't really think much of it because I'm like turning 40 and I've had some back issues.

And, I had just gone in to see my new primary and everything was fine, normal. And I just sort of mentioned to my dad, who is here too, that the odd thing was that I was having some sort of tingling in my fingers and, both fingers, and he said, that is a little strange. You should probably go in and...

My dad is a retired family physician from Two Harbors, and when he says I should go in, I'm going to go in, because as a kid, he'd be like, Oh, you broke your toe, well just bandage it up. Keep walking. You'll be fine. You know? He tells me to go in, I know that it's something to get checked out.

Kevin: It's just a toe, you've got nine others, don't worry about it.

Zoey: Exactly. Yeah. And so, I did go in a couple of times before they decided it was something they needed to look at with an MRI. And still at that point I was thinking, Oh, it's a pinched nerve, or, you know, one of these things that happens. And it was, I think around like January 15th or so when we had that polar vortex—I think they named it, made it really dramatic—and I had gone in for an MRI and I woke up the next morning to a bunch of missed calls from St. Luke's, and it was kind of a whirlwind after that. I was told I had significant lesions in my spinal cord covering, called transverse myelitis.

And luckily my friend, my best friend's a nurse and she came in, we went in to see the neurologist, that day—there had been cancellations and things, and it was that urgent, that they got us in. And I'd worked in vocational rehab for seven years. I've read thousands of stacks of medical records, literally. I know quite a bit about MS and other neurological—I'd never heard of this. So it was a shock.

Kevin: So what did you do first? Once you found out that's what it was, what did you do first?

Zoey: I think I, I mean, I'm still sort of processing it. My friend Mary was with me and she's a nurse, so thank goodness she was taking notes and could kind of help. And then my dad was on the phone also. He was in Colorado. But that day it was just a whirlwind. It was like six medical appointments, labs,

and then they started me on IV steroids, um, that very day and for the rest of the week.

Kevin: So put yourself into that moment of, just got done with six medical appointments, and thank heavens you had great support because there are a number of people who come to medical appointments and they think, yeah, it's just something, it'll be fine. I can drive myself, whatever. So it was really smart of you to be able to have people that you trusted that also had medical background to be able to be there. It isn't true for everybody.

Zoey: Right. I don't know what ... I don't think I would have remembered a single thing that was told to me in that appointment if I didn't have someone there with me.

Kevin: So, at the end of those six appointments, I understand that you, that it's kind of a blur, but what were you feeling at that moment in time?

Zoey: Well, one thing, it was a relief, the neurologist I saw actually knew my dad. We had sold the sailboat from Caribou Lake to her. I mean, it's Duluth.

So these things happen. So that made me feel relieved that I knew that she was going to have direct communication with my dad. And, and I think—I was honestly so exhausted, I don't know what I was feeling. And then they kind of tell you, Oh yeah, steroids, they might make it hard to sleep.

Well, nobody told me that you're physically not going to be able to sleep. And so, like, it was actually kind of like mania because of the medication at that point took over. And, nobody really prepared me for that until I started to read about it and be like, Oh, this is what's going on.

Kevin: So you did do some research?

Zoey: Oh, yeah. It's nice that I had a background in medical and knew a lot about related conditions, so I, if I was trying to understand something like this and like demyelination and things like that and never having known about it from my work background. I don't know. I would have taken a lot longer to even understand what was going on.

Kevin: And think about that situation for somebody who wouldn't have had the knowledge that you had or the friends and family that understood medical situations as well. We so often don't appreciate the fact that so many people are on their own, and even in your work, in voc rehab, so many of those people are struggling with so many things without any kind of support or knowledge to be able to work through it.

So, manic state, how long did that last?

Zoey: It still, um, I've been on, had to be on steroids now for, oh, it's going on 11 months. They're able to start tapering me off. But I mean, I can definitely tell it changes your mood and things like that. And so that's sort of the next part of my journey is there's going to be some sort of, you know, crash or decline, and I'm prepared for that. But it's going to be, that's going to be kind of the next difficult thing, is managing that.

Kevin: So can we talk a little bit about your condition?—because it's not familiar to many of us, if any of us, I take it, it's pretty rare. We understand what your initial symptoms were, but talk to me a little bit about the disease process and looking forward and all that.

Zoey: Well, I think the first challenge was, transverse myelitis is just, is a term for lesions in the covering of your spinal cord, the myelin sheath. And it can be caused by about 2000 different things. And so the very first thing, they treat it with steroids, no matter what it is, to try and stop it from getting worse.

But then the next step is to really figure out, well, what caused it so we know how to treat that. And you know, it can be things like multiple sclerosis or Lyme's disease, even. So it's this ruling out of everything else. And without, like, my dad's support and really pushing for that, he did a bunch of research and found some articles and we found a specialist at the Mayo.

And they were able to determine that in my case, the cause is what's called neurosarcoidosis.

Kevin: Okay, help me out with that.

Zoey: Yeah, exactly. I'm like, what?, you know, and sarcoidosis in itself is, can manifest, usually people think lungs and when it is in the spinal cord, that's pretty rare. So here I am in this like tiny percentile of people that have this and it causes this damage.

But we're, you know, lucky enough that there is a doctor that specializes in that at the Mayo and was able to confirm that diagnosis and then the treatment for that is—steroids. But, just getting to that point was huge because a lot of people will have what's called idiopathic, which, I think my dad explained is, the word idiot is in there for a reason.

It means they can't figure out what else, you know, and they may have relapses then because they have never truly figured out what's causing it or how to treat it.

Kevin: So tell me a little bit about, I assume that you've had lots of medical appointments ...

Zoey: I think at least 50 or 60, and hit my deductible in February, I started my insurance, you know, I mean, yeah. It was more than I've ever had in my life. It happened fast.

Kevin: So the first appointment that you had at Mayo, can you describe to me feelings going into that appointment?

Zoey: Well, I had talked with the—a big resource I've used is an online forum called the Blue Crew or the Transverse Myelitis Association.

And it's a Facebook group of people that either have it or have family members. And so I had just chatted online with a woman whose husband had it, and she referred to the Mayo as medical Disneyworld. And when I got there, I thought—I'd been to Rochester for work not that long ago—and I thought, absolutely.

I mean, it was beautiful. I got great care, and there's so much money there too. It was just sort of like, Oh, there's a grand piano. There's a famous work of art. And, it was overwhelming, you're—my dad was with me, and you just kind of are shuttled around, again, to about five or six appointments a day.

And I was really impressed with my neurologist and, and you know, everyone working there, but it was very overwhelming.

Kevin: We talked a little bit this morning about design and how design can feel comforting but also a bit overwhelming. And oftentimes when in health care, we can look at situations where it's not about the building, it's about the care. Do you have any impressions about that?

Zoey: The one thing that has been challenging, and I've seen this in my work life too, is, I'm trying to coordinate between local care here with St. Luke's—I have a great family physician—and having a specialist at the Mayo and just trying to even just get medical records to go back and forth smoothly or get people to talk to each other.

It would be a lot easier if there weren't like different, two different institutions in place that have their different rules about releasing medical records and you know, it's hard. It's really hard to coordinate.

Kevin: So after that first appointment, you're on the drive home, you're coming up 35. What were your emotions after that first appointment?

Zoey: Well, I had just had a lung biopsy to, that's how they confirm sarcoidosis. And, I think I was telling my dad, Oh, I could drive. And he was saying, Nope. And I think I was pretty out of it. There was ... and it was really, really snowy. And I remember us getting just north of the cities and thinking, yay, we made it through traffic. And then it was like a dead end traffic stop. And it was, yeah, by the time we got back, just exhausted.

Kevin: Okay. So you get home and you settled back in with your family. How has family life changed with all this?

Zoey: It's hard, because we're busy. I have two stepdaughters, they mountain bike race, and at first I was just like, well, I, you know, I'm going to keep working. I worked 32 hours a week at that time. You know, I had some sick time built up and I was trying to juggle working and just doing normal stuff for a month or two before I realized something's gotta give here, and I reduced my hours. Luckily, I know how FMLA works and I know how to advocate for that through past work and was able to take some time off and my job was flexible. But, talked to other people where they've had to maintain trying to work full time or they're going to lose their health care and they don't have money and I can't even imagine

Kevin: Supportive life at home?

Zoey: Yeah. I think—my husband works in occupational therapy—and he had actually worked with somebody that had transverse myelitis, although it looked completely different. A lot of people will have it where it impairs their motor function. For me, it's sensory, and so he had worked with someone who was temporarily paralyzed, and was in recovery, so he had some understanding there.

But it's still been really hard because I'm a very, usually a very physically active person. I'm still able to do quite a bit. But, I also have a lot of discomfort and strange symptoms and side effects from medication. And, like, I used to bike to work almost every day and I'd run every day and I haven't been able to do that, since right after getting diagnosed.

Kevin: Which changes everything. So you mentioned that yours is sensory. Can you give us a little bit of a feel of what that's like for you?

Zoey: Yeah. So I have numbness or neuropathy, um, in my arms and legs, and on both sides. I have no temperature control, so I can't feel any heat or cold, especially on this hand. It just, it's hard to explain. It's like reading an Oliver Sacks case study. It's very strange. I feel there's a lot of pressure that builds up throughout the day and it almost feels like I'm being crushed, which is not really—it's very strange, and so I have to do a lot of stretching

and I get really tired ... usually try and lie down around noon, but can't necessarily sleep because I'm on steroids. It's like being kind of manic and exhausted at the same time. It's, it's hard.

Kevin: So tell me what a good day looks like for you, now.

Zoey: Mornings are usually best for me. I have to take sleeping medication to physically sleep; I had tried without that, and it just, I mean, I would literally be awake all night. So I still wake up quite early. And then I will stretch and go for a walk. And I, and I feel pretty okay in the morning. I do, have been maintaining work still, part time, which I'm doing through January to keep my insurance.

And so if I'm working, I'll work in the morning. And then I usually, again, need to come home, stretch. It's kind of like a full time job, just trying to feel as normal as possible. And it's still—I can't make it up much later than about nine because I'm just too uncomfortable.

Kevin: So what does a tough day look like? Either physically or emotionally?

Zoey: It's, sometimes the day just feels so long and like, it's weird because I'm used to having a full-time job and the day goes pretty quickly. And it's kind of like the screen door metaphor. Like I've stepped outside of that world and I'm kind of watching it.

And it's hard because it's sometimes it feels like I'm kinda out there on my own—and those are the hard days.

Kevin: So were there moments in time when you felt like you didn't get the information that you wanted?

Zoey: Yeah, and there still are. I mean, I think the talk earlier about it would be nice to have—like I have friends and family that advocate for me and I know there are social workers, but sometimes it feels like nobody's driving the bus, or I am, and I don't know if I should be—and so, you know, if there was time and resources for somebody who could kind of say, Hey, we're pulling this all together, and here's what was said, because you do forget things when you're going through trauma and you're overwhelmed and you're on medication; even if you come from a place of understanding that world, it's completely overwhelming when you're in that world.

Kevin: Well, I think it's this weird balance of patient driven care and expert knowledge, and it has to be a balance of both, and you can only make good decisions if you have the information that you need in order to make those good decisions. Right?

So, in the presentation you heard me talk about the value of the moment that everything changed and it's not about that diagnosis day, it's about the moment when you decided that you were going to move forward, that you were going to be in charge of your future and that you could see the future from where you were.

Do you have that moment in time?

Zoey: I think I took, I think I've gone through moments and I still am. There was a moment, like the summer was really difficult, like with multiple sclerosis, symptoms were, for me, are worse with heat. I didn't like heat to begin with.

Kevin: Welcome to Duluth—you're in the right place!

Zoey: Thank God—I couldn't be anywhere else.

I had to travel down, to work, to the Cities for work, and I just realized it was too much for my body and decided I was going to take a leave over the summer. So that, I think was an important, like, Hey, I need to give myself time to recover.

And then I more recently decided that I am going to be taking a leave from my job more permanently and just giving myself time to recover, spend time with family and work on art, which I feel like when I, when I'm painting, actually I should say, I tend not to notice my symptoms because that's something that I enjoy so much and I get so absorbed in, that it just takes me to another place for awhile.

And I figured that's what I need to be doing, is things that make me feel that way until I hopefully am feeling better physically, overall.

Kevin: And what is the prognosis for you moving forward? What's your thought about it and what, where do you see yourself?

Zoey: Yeah, it was frustrating in April. I had started tapering down on steroids and that showed that just things weren't quite healing as quickly and I had to go back up. So that was, that was hard for the summer. But when I went in last, for an MRI, that showed significant healing. And so what we're kind of waiting for now, I've been able to taper some slowly.

So getting rid of some of the bad side effects from being on steroids is part of it. And then with neurological damage or symptoms, I'm just keeping told we don't really know. It's slow. Be patient. Be positive. You mean it's just sort

of a waiting process. The prognosis, like sarcoidosis, typically in the spinal cord, it's not going to be other places or pop up, most likely.

But it's so rare. There's not like, you try and read studies about it and there's just not very many because it's so rare. So it's a lot of unknown. And a kind of a lot of, well, let's wait and see. And I just have to be okay with that.

Kevin: So what has been the most frustrating piece of dealing with health care for you? It sounds like you had really good experiences locally, really good experiences outside with specialists as well, but what's been the most frustrating piece of it for you?

Zoey: That coordination piece has been a bit frustrating. I think one thing, I wish that, I mean, in this case, they truly don't know that much about what it feels like, and how to treat nerve damage.

And I think my doctor at the Mayo wanted me to be hopeful and he said, you know, I think things are going to kind of table off from here. And then when I started to feel worse after that, that was scary. And for me, I think it's okay to just say, we don't know. This could happen or this could happen. And you just have to be prepared. I'd rather hear, I don't know, than, you know, something, more, I don't know, hopeful than, 'cause then I was scared after that when it was like, Oh, now I have symptoms in my knees and my legs. Now is that normal?

Kevin: So what's that about? I mean, sure. The unknown would be difficult for sure.

So let's assume that we have a whiteboard, and the whiteboard says, this is what's most important to me—with a blank line. What are you going to put on that line?

Zoey: Um, I think accurate, realistic information and then just laying out like the next steps, like literally like, here's what to do or what to expect or what we do know for the next few months, because even being told that a few times, I'm always kind of like, Oh, what's next? Am I supposed to be doing some sort of test or, you know, it feels like I'm always trying to kind of keep up with what I'm supposed to be doing next, so I don't miss something. Um, yup.

Kevin: And what are your hopes for the future?

Zoey: So actually, today they are interviewing at my job for the person that's going to take my place in my position.

Kevin: I bet that's weird.

Zoey: It's really weird. But I think the cool thing is, is that I will be able to kind of train that person in and show them my job, and know that that work will carry on.

And then I'm really excited to just—I'm planning in my mind kind of a six month, not having, I've worked in human services now for 18 years—so having a break from that for six months to focus on art, and kind of where I may go next with that, is really exciting.

And just a shameless plug for myself—if anybody's doing ax throwing at the Blacklist Brewery, that just happens to be where my paintings are. Yeah.

Kevin: There we go.

Zoey: Please don't throw axes at them.

Kevin: And that was shameless.

Zoey: Totally shameless.

Kevin: Did you just put them in there like yesterday?

Zoey: Yeah, I just, they don't even know. They've been wonderful—I have a friend that works there, but they had my stuff up right before I was diagnosed. And they said, you know, you're welcome to put it back up, and I've sold a few works there and they don't take any commission and they sometimes just pay us in beer too.

Kevin: Nice.

Zoey: They've been a great local business to work with.

Kevin: Cool.

So ... if your health care provider really knew you, what would they know?

Zoey: That I have a sense of humor. My neurologist—wonderful—he has an Irish accent, so I love that. But, we've joked around with him a little and it kind of freaks him out because he's like, wait, you're in here for this serious thing.

But that kind of helps me cope a little bit, and I think my dad too. It's okay to be a real person around your patients, I would say, I mean, that's been difficult for me just working in voc rehab. It's like there's this, "I'm the professional and you're the client" thing. And I mean, yeah, you have to have

boundaries, but that's a construct; we're all just people, you know, and that's okay.

Kevin: Great. So I'm going to give you a magic wand, and the magic wand will only do one thing to change our health care system. What are you going to do with your magic wand?

Zoey: I am going to make it so that health insurance and paying for things is not tied to how much time and energy a person is able to put in to spending with their patient.

Kevin: Great. Is there anything else that you think is important for me or for us to know about?

Zoey: I think both having this medical condition now and working in disability advocacy is that, again, to realize there's not this divide. Like we can all switch over into one of those roles. You know, working as a professional or having a family member or experiencing an illness or disability yourself, and it changes how you see things when you have to switch over.

Kevin: I bet it gives you real insight into the human condition, not just your condition, but the human condition.

Zoey: Yeah. It's made me more compassionate in my work or I think come from a different place of understanding.

Kevin: Great.

So from the one phone call that we had, I knew from the very beginning, first of all, that you did have a great sense of humor and the video shows that too, which I think is very cool.

[Speaking to the audience] Zoey is willing to answer questions about things going on for her too; please remember that this is a really brave thing to do, and if you can find those people in your practice, in your hospital, in your community, it will give you a new purpose for why we do what we do.

So we'll open up for questions.

Audience member: First of all, thanks Zoey, very much. I wondered about when they prescribed the steroids. Did they tell you how you would feel taking that amount of medication?

Zoey: Uh, yeah. A little bit, but, first of all, I think that people experience it differently, too. Some people, it makes them gain a bunch of weight and slow down, and other people, it makes them manic and lose weight.

So it was like, Oh, it could go either direction. We'll just see. And so I think they don't—they know a bit about it—but they don't truly know what it's going to be like until it's you experiencing it.

Audience member: Thank you, Kevin and Zoey, this was really remarkable to experience. My question, you talked about the coordination piece and you talked about that not knowing what to do and not even, being at that first visit, not even, maybe not able to hear everything. How would it—Kevin asked too—about if it could be anything, what would that, I'll call it a person because it has to be a person, but call it a person. But what would that role look like in your life as a patient? Walking through all of those things?

Zoey: Well, I work myself in disability advocacy and so I picture, you know, somebody in the role of like, Hey, let's check in monthly and review your records and what's the next steps and kind of, what you need to be planning for next. Which, kind of, my dad and family and I have done. But I don't know what somebody who didn't have that support would do. Literally.

Audience member: Hi, Zoey. Well, I just want to make a comment, I think it's amazing how the system, what I've seen, is that when they give a diagnosis, they don't even give you time to process it, and they just rush you into the whole system of, now you go to A, B, C, D, E F, G, H, till the K, maybe by the K, you kind of realize what you're going through.

But I think, well, from my perspective, any disease is just an unresolved conflict. But sometimes the disease itself might become another conflict. So my humble suggestion is that you address the emotional trauma from the diagnosis, that you really address it in a deep level. So this conflict doesn't become another conflict. You know what I mean? So that's just a suggestion.

And another thing in the medical system, like if we really want to make a difference, give the patient time to process. Because once you get at diagnosis, I think all your body's going different direction. Like your mind goes one way, the emotion go another way. Your physical body doesn't even know where it is. And then the medical system, just because they want to rush things into the money, they don't even give you time to process it. So good for you that you had this, you know, the support in your family.

But maybe you can share this with a lot of people, you know: please, people, give time to yourself to process it and to make a right choice, not just for what everybody tells you to do. And it took time for you to get to that point. So no rush, no, not even cancer. So no rush.

Audience member: It struck me that, Kevin, you said our goal should be to go from patient centered care to patient driven care and that you, Zoey, said you were at a point where you didn't know who was driving the bus.

You thought maybe you were driving the bus, but you didn't know if you should be driving the bus. So this driving theme, I'm wondering if there's anything that your provider or caregivers could have done, that would make you feel confident that you should be driving the bus?

Zoey: Well, I think part of it is just being, you know, on so many medications and things like, I'm used to being in charge of myself, and my family and things like that.

And, you know, it felt like I wanted to be able to hand some of that over and say, I just need some help being taken care of. Or, you know, making sure somebody's drawing this all together cause I'm, I'm exhausted. And I can't remember all this right now.

So I don't know if that answers the question, but it was like, I think, you know, for me, being an independent woman, not getting married 'til I was 37, and I'm used to taking care of myself.

It's almost harder for me to hand a little control over, but I think that maybe is what is or was needed.

Kevin: Plus a piece of it from my perspective is the idea that Zoey is in control of the situation and it's absolutely fair for her to say, I need help. And drive even those ideas of, wait a minute, I don't understand what you're telling me.

Or, I need you to give me a recommendation as to what the best plan is. That doesn't change the fact that she's still in charge. She's still driving the bus. So even saying, I don't know that I should be driving the bus right now, I need help, is still allowing her to be in control of that situation rather than the health care system being in control.

It's a different perspective, and you [turning to Zoey] may not even know what you need in a particular moment, but being able to drive that discussion and, and drive the questioning. Oftentimes we say to customers, do you have any questions? And oftentimes the response is, no, I don't have any questions, because we're taken aback by that idea of, wait a minute, now I'm put on the spot.

And yet if we really drill down with people, they do have questions and they're just going to take them home with them, rather than take care of

them at the moment. So it's the reality of who's in control that I think is most important. It's not about always having the answers.

Audience member: Hi. Thank you for sharing your story.

One of the things that I have done in my career at the Mankato Clinic is what we called customer service training and I really tried to appeal to people's emotional intelligence, you know, in how they approached their role. But it occurs to me, even with Zoey's story, how, the industry is so regulated and it's moving so quickly and you know, we have all these quality measures that have to be, you know, taken care of, and we have to document things.

And, I had a nurse share amongst her peers, a story about asking a patient if she had fallen in the last six months. This was a new initiative at the clinic, and the patient said, well, why do you ask? And the nurse's response was, well, this is just another question I need to ask you. You know, it's just something that was added to this list of questions. I'm sure there are going to be many more, you know, in upcoming appointments and you know it sort of strikes me that we're just not doing the best job helping our employees understand a lot of the things that you're talking about. And then how do they help you?

Kevin: It's about understanding purpose. Because it's not about filling out the form. It's about getting vital information in order to make sure that the care plan is right and it's too bad that people don't understand that innately.

But many people don't. So we need to be able to do teach-back, like Vicky talked about this morning, with our staff, not just with our patients and our customers. Because sense of purpose will drive the work and will hopefully eliminate some of the burnout that we're experiencing for health care workers as well.

If we can get back to what the real sense of our work is, then it's easier to go to work every day. In doing leadership training with people, we talk with them about what do you say to your employees at the end of the day. What doesn't work is to say thank you for your work. Thank you for your work.

You know, what we need to do at the end of the day, or the end of the shift, or the end of the week is to say, what do you feel good about in the work that you did today? Because that sense of purpose—this is by far, too hard work to not understand why we're doing it.

Kevin (to Zoey): Do you have any comments about what she had to say?

Zoey: I think, yeah. I mean, I know that there's routine questions that they have to ask, and I think I know what they all are. I think I verified my birth date about 3000 times this year, and that's okay. I know they have to do that.

I think the other thing is just remembering that we don't all speak medical lingo. So I was going to pick up my husband just yesterday and I see St. Luke's calling and the lady calls, Oh, we have this test scheduled. And I'm like, you need a bone density scan. Like, just say it. And you know, I have no idea what the technical word is and you probably don't know that I don't know that. But, you know, just translate it and make it, use plain language for people. You know, make it understandable, I guess.

Audience member: So a comment and then a question. First of all, this whole jargon around patient driven care, really strikes a chord that's uncomfortable for the health care providers and truly, the patients, you know, need to be in charge of their care.

But I really wonder if we wouldn't be in a better place if we really called this relationship driven care. Where there is a partnership, a true partnership between patient and the caregiver team, and really got out of the notion of physician driven, patient driven. It's really a joint driven journey.

And the jargon actually can turn a lot of people off. So we've gotta be careful about that balance. That's a comment. The second, the question that I have—Zoey, first of all, thanks for sharing your story. Really appreciate it. There's so much to learn from that.

I wonder if you can comment on the times where the conversations were difficult. The news was not easy. The message was perhaps difficult to hear or even incorporate. If you could comment about how you perceived the professional, the physician, nurse, whoever was giving that news, how you perceived their dealing with delivering that message?

Zoey: I think it was probably most difficult or confusing when I first got diagnosed. Or when they first looked at my MRI and saw how significant the damage was, and they were so confused as to why I wasn't doing worse. And, you know, I guess I was like, well, I'm glad I'm [?]. Like, usually people would be coming through the emergency room and, but, that was also scary because they didn't, they weren't sure why, they didn't know the diagnosis. So, I mean, I think they were actually kind of working through that thought process as they were talking to me, and that was a little bit difficult.

But I think, some of the positives: one really great thing about the doctor I work with at the Mayo is that he corresponds with me via email really quickly. And so when I'm anxious about something, whether it's a new symptom or a

medication side effect, I can email him and say, Hey, this, this, this, and this is going on and know that I'll hear back fairly quickly and that it's written down so I can look up the words I don't know, and reread it, and share it with my dad. And that makes a huge difference in just my comprehension of it and ability to kind of process it.

Audience member: Thanks. So I just want everybody to think about for a moment, what it's like to be on the other side of the conversation. And as I said, I'm a medical oncologist, so I dealt with a lot of giving difficult news, for a whole career.

It's not easy. And a lot of the time we say, Just give us more time, let them process. But we, ourselves, as providers are in an uncomfortable spot. And so what happens with that is we speed up, we jump the gun, because of our own sort of, our disquiet within us.

And I can't emphasize enough that, you know, if we're going to get this right, we cannot assume that our providers have the right skills to really pull this off. It's really difficult to do. And you can say that's their profession—that is; they're human beings, but it's an important part of the equation that we have to pay attention to.

This whole thing of asking the question, do you have any other questions? That's the wrong question to ask. A yes or no question is the wrong question to ask. That's part of the joint agenda setting that I was talking about. We need to be able to do that in a different way where we truly open the door for our patients.

So as you go through this, don't just think that that the health care team can just switch like this and make a different conversation. It will not happen. So I just want to point that out, there's two sides to this puzzle and we need to work on both sides.

Kevin: For sure. I love that idea of relationship driven care. That's a great concept. I love that.

Audience member: Just riffing off what Dr. Maples said, sort of about the jargon. I think one of the changes in the way that we—the names we give providers and patients—so you referred to patients as customers and [?] that's not driven by us and it makes me uncomfortable, if we're really, in the way you talk about it is it's like a really important and privileged relationship that we have with our patients.

And it's not like we're selling something, so the term customer makes me really uncomfortable. And I don't know, Zoey, how you feel, if you feel like

being called a customer is something that you prefer over a patient or what? I've always wondered that, and it's not like I ask patients this all the time, but that's one thing that—the way that it's gone—and it's not driven by us, but that's sort of the language that's now out there.

In my training, it's, you know, do you have any questions? The way I was taught and it is slowly changing, is that you're opening the door and saying, what questions do you have? It's a subtle change, but then you're not necessarily assuming or putting them quite on the spot, but you're opening the door, and that language, I think, helps.

Zoey: So you're saying an open ended question instead of that ...

Audience member: Right—what questions you have?

Zoey: Yep. And I have been trained on that with vocational rehab. That's how we did our—we trained in motivational interviewing and, you know, I would have subjects I needed to cover, but I would start off with, What brought you here in terms of finding work today?

And that would get me a lot more information than, well, Why are here—that open-ended. It works. And then as far as the ... um, I like to make fun of the billboards in Duluth that are like, Hey, come get your MRI here. Like, I'm going to shop around for an MRI when I like, you know, it's ridiculous. So I agree. Like I'm just a person, a patient, whatever, it doesn't matter, but, no, I'm not going to be out like, Oh, I think I'm going to go get that MRI at St. Luke's, 'cause look at that billboard, you know, it's just, it seems really fake to me.

Kevin: We often, in this whole realm, get into the discussions about consumer, customer, patient. It's one that I don't think that there's a clear answer to, but I can tell you, at least from my perspective, the more horizontal you are, the more you are a patient—and the more that you are vertical, the more that you have opportunities to make choices.

And loads of people are making choices about their care. They're choosing to either stay with a particular group or they're choosing to go somewhere else, and oftentimes we don't even know that they're gone. And for me, this idea of customer is not about the transaction of money. It's about the relationship.

And there isn't a clear answer about it. But I think the more that we move into an environment where people have choices, the more they are consumers, the more they are customers. Because choice is about being able to go the

direction that I want to go. So it isn't necessarily about the discussion in the room with your patient.

It's more about the kind of decisions that they're making outside of that relationship to either stay with you or to go somewhere else, and that's where I fall on the side of "customer." Again, it's not about how much am I willing to pay for that particular visit today. It's not as simple as that because it is about relationships, but people are choosing to go somewhere else. That's a customer relationship.

Audience member: So I just want to follow up. I think we need to be, again, careful on jargon. I would never, ever, ever want to have a relationship that I have with one of my patients be described as "a customer." That relationship is so much more sacred than any customer relationship could ever be described.

It's true that they can shop and be competitive and go elsewhere. That's our job, to really do our job better so that there isn't that need to do that, but the relationship between patient and physician is at a sacred level, which is much deeper than anything you could ever, ever describe as a customer.

So we just have to be a little bit careful when we use that terminology.

Audience member: I agree. And I don't agree. I think that that's a ... I'm hearing that as a perspective, as a provider, you're a provider, I'm a health care provider.

When I'm a patient, I feel like a customer because I have some really sacred relationships with other providers of service in my life. Right? And if I get disappointed in those relationships, I will find a new provider. And so, I think what I hear in what you're saying is, we don't want to disregard it as not a sacred relationship. We have lots of sacred relationships in our life that we could probably really think about this "customer service," and that's where I like the term, customer brings to mind service. And I think sometimes as providers, and I say this as a provider, we forget that we're providing a service that people can get elsewhere. And if we don't do a good job, exactly what you're saying, they may leave us without telling us why.

And as a provider, that's heartbreaking, right? That your person leaves and you have no idea what you did or you didn't do, or the system did or didn't do, or why did they, where do they go? So I think the thinking about patients as customers is not a commoditizing way for me in the way I think about it—it's a service. That seems important to me. So I think it has value in how we approach it and, and people are going to call it lots of different things. What you want to call it, what I want to call it, what you want to call it, what

Zoey wants to call it—only matters in the little sphere of our minds because there is a lot of difference and variety in people.

Audience member: This is a term that has sort of come into my life more recently, in the context of business, and the term "stakeholder." I don't know how that feels to anyone. I'm reading the book "Conscious Capitalism," and he talks about not just shareholders, but stakeholders, which are, you know, the people that you're serving and your employees and the earth and the environment and there's all these different people and entities that hold a stake in what you're doing in that provider/patient relationship. And I don't know if "stakeholders" is maybe something that is sort of in between a patient and a customer. I don't know.

Kevin: At a strategic level, we talk a lot about stakeholders. So it's interesting to bring that into this realm. I hadn't really thought about that, but that's an interesting concept because it is a piece that we do talk about, but we talk about it from a strategic point of view, not a personal relationship point of view.

Audience member: My name's Judy and I'm Zoey's aunt, and so I'm not a health care professional, but I was just thinking about this as she's explaining and, and having known her story, how fortunate she is that her father is a doctor and that she was able to call him and he was able to come and be here and go to appointments with her and that most people don't have that and how alone people feel, if you are either the person having the procedure or if you're like the loved one of someone and you don't understand and doctors aren't bringing it down to your level, and if there were some way to have, you know, some other health care, social worker, or somebody who could be there for you.

I know, my husband died very suddenly of an acute case of leukemia. He was diagnosed in the morning and died that afternoon, and I had no one there to help explain what was going on. And so, you know, I don't know if the system provides for that, but you know, to have somebody who has some kind of medical background other than the doctors there with you, I think was wonderful in your case, and to know that lots of people don't have that.

Kevin: I'm sorry for your loss.

Zoey: Yeah, I agree, Judy, that was a really hard day ... We were, I mean, having my dad, having my best friend, having, you know, my husband just know that world. But on day to day, I work with people with disabilities that are here on their own, and the only people in their lives are maybe paid staff and they're trying to process this.

And a lot of the people I work with have developmental disabilities as well. So I think using language and terms that people can understand—it's important for me, but it's even more important when you are there alone, and having something that you can take with you from that appointment to help you, you know, have something to look at and process when you're on your own again and trying to process through all that.

There's a disconnect there for sure.

Audience member: Hi, Zoey. I was wondering where did you go to learn more about what you were going through, and what was that experience like for you and how it could have been made better?

Zoey: My dad did a lot of research and he actually found an article and a research study done that my doctor at the Mayo participated in or helped write. So I read that.

There's a really great book that just came out, by a gentleman—who started the Transverse Myelitis Association, that I'm in the middle of that talks about patient experiences—a gentleman whose wife had it. And then I've just done a bunch of research and reading on my own.

There's, like I said, the Transverse Myelitis Association. There's a sarcoidosis foundation, so I will periodically kind of just read and review. And then I've requested all my copies of my own medical records as well as the ones that are online. So sometimes I'll just go back and kind of read through that and be like, okay, this is what's going on.

It helped, though, having a background in vocational rehab just to understand some of the medical; it would have been a lot harder without that background.

Audience member: So of course I'm Zoey's dad, and I'm the one who had the experience of the patient advocacy. And it occurred to me that we have a whole cadre of retired health care professionals with a lot of background knowledge, and wouldn't it be a good program to involve them in patient advocacy as volunteers in difficult cases like this?

I don't really know of any organized programs like that. I've just done it unofficially for others besides Zoey, but it would seem we would have a whole group of trained professionals who would be eager to participate in this way in the health care system.

Kevin: What a great idea.

Zoey: So if anybody is hiring for that position, I think I would be perfect for that role as I'm kind of going independent here. Hint hint.

Kevin: Sounds like you have to stand in line behind your dad.

Zoey: Ah, yeah, he's too busy skiing most of the time though.

Kevin: Any more questions? [To Zoey:] I love that all the questions are coming to you.

Marsha Hystead: Well, thank you very, very, very much, Zoey. Been working on this for awhile.