

# Quest

## PODCAST



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### **Episode 41: Courage Kindled: A Hero's Unbreakable Spirit**

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**Mindy Henderson:** Welcome to the Quest podcast, proudly presented by the Muscular Dystrophy Association as part of the Quest family of content. I'm your host, Mindy Henderson. Together, we are here to bring thoughtful conversation to the neuromuscular disease community and beyond about issues affecting those with neuromuscular disease and other disabilities and those who love them.

We are here for you to educate and inform, to demystify, to inspire and to entertain. We are here shining a light on all that makes you. Whether you are one of us, love someone who is, or are on another journey altogether, thanks for joining. Now, let's get started.

Ken Sutcliffe dedicated his career to saving lives as a US Army veteran and as a firefighter. He never thought that one day he'd be fighting for his own. Today, I am so proud to introduce you to Ken, who was diagnosed with Amyotrophic lateral sclerosis, or ALS, also known as Lou Gehrig's Disease, and his wife of 13 years, Andi.

I had the great pleasure of speaking with both of them a week or two ago, and they quickly became two of my favorite people on the planet. Their strength and positive outlooks are infectious, and not only were they both heroes in their careers, but they continue to be heroes to so many as they spend their time raising awareness for ALS and raising money for research.

Ken, Andi, I am so happy to have you here today and to have what I know is going to be a wonderful conversation.

**Ken Sutcliffe:** We're so excited to be here, and thank you for having us.

**Andi Sutcliffe:** Thank you, Mindy. It's our pleasure.

**Mindy Henderson:** Thank you. Well, I'm going to jump right in. You two have such an interesting story of how you met and some of the incredible work that you've done together. Can you tell us a little bit about your love story and how it all came together?

**Ken Sutcliffe:** I'll be happy to start it. Andi can jump in, but most firemen have a second job. They have a side hustle since you work, for us, it was 24 hours on, 48 off, and mine was working for movers, and they'd let me know the day before where I needed to be to help do moving, and got a call to go in an address to help do some moving. Lo and behold, little did I know I was going to meet the wife of my life that day moving her out of the house she was in and into another house. So we met moving. I don't know. What can you add to that, my love?

**Andi Sutcliffe:** Well, the love story continues. He pursued me for almost a year and would send me flowers and they would say, "Patiently waiting, fireman Ken," which was adorable but annoying at the same time. I was raising my youngest son and my focus at that time was just on my son, but how Ken won me over was I'm a huge hockey fan and he offered to take me to a Stars hockey game, and finally after a year, I agreed and I said yes. So that's kind of how it all began.

**Mindy Henderson:** I love it.

**Ken Sutcliffe:** Our first date was a hockey game with hockey fights and hot dogs and popcorn and everything else, and we had a wonderful time.

**Mindy Henderson:** That sounds like a perfect first date. Now, if I'm not mistaken, didn't you both also maybe work together on the search and rescue teams?

**Andi Sutcliffe:** We did.

**Ken Sutcliffe:** Yes, we did. Of course, when we both got onto the search and rescue teams, this was after we met. Where I was working was the technical rescue station for the city of Dallas at the time, and we did all high angle, low angle, confined space, any kind of rescue that a normal engine or truck company could not handle on their own.

**Mindy Henderson:** Wow.

**Ken Sutcliffe:** They would call us in to do it. And because of that, we had once urban search and rescue team in the entire state of Texas at the time, and that urban search and rescue team was Texas Task Force One. Well, lo and behold, of course, they were deployed one day and the governor decided, "You know what? I need more search and rescue assets." So he tasked Dallas Fire Department to step up and create an urban search and rescue team.

**Mindy Henderson:** Oh, wow.

**Ken Sutcliffe:** And that's how I ended up on an urban search and rescue team and became a member of that. And then later on we brought Andi aboard, kicking, screaming, I might add.

**Andi Sutcliffe:** Let's clarify this. Ken came to me and told me they were going to get four new dogs. I was an EMT and at one point I had done my training and then volunteered as a victim for search and rescue dogs, and I thought, "What a great combination, the dog, the medical aspect." And so I applied through the National Disaster Search Dog Foundation out in California and interviewed.

And I have to say in my interview, it was with the Dallas Fire Rescue because they were the sponsoring agency, I felt like you have to bring your significant other. Ken pretty much stole the conversation and at one point I'm like, "Is this interview for me or is it for you?" Fortunately, I was selected and so from there began my career as a disaster search and rescue canine handler, and I was a member of Texas Task Force Two and worked in the program office and then also part of Texas Task Force One. So that's kind of our love for the search and rescue. Ken was a search team manager on a deployment. He was my boss.

**Mindy Henderson:** Tricky.

**Andi Sutcliffe:** He'll say no, but he was. So we got to deploy a couple times together, but for the most part, we both had a love for search and rescue and just to give back and to help other people. And I think for me, it all happened when 9/11 happened and I wanted to be able to do something, didn't have the qualifications for most things, but I knew the dog was an avenue to get me to be able to help and do that kind of stuff. And through Ken and Dallas Fire Rescue, I was able to achieve that, so it was great.

**Mindy Henderson:** That's incredible. I can't imagine what hard ... I'm sure very difficult work, but also I would think such rewarding work.

**Andi Sutcliffe:** Completely. I would tell Ken, I said when I was sweaty, dirty and sitting there and getting dirty with the dogs and training when it's 120 on the concrete, that was my best time. Again, it was hard work, it was rewarding, but I wouldn't have changed it for ... just like him and the fire department, wouldn't have changed it for anything in the world. It was a great bonding for us too. We obviously became closer. We weren't married at that time, so it was great for both of us.

**Ken Sutcliffe:** Yeah, I got to carry all her bags.

**Mindy Henderson:** Oh, I love it.

**Ken Sutcliffe:** I'm a reporter.

**Mindy Henderson:** Yep. Well, I don't do search and rescue of course, but I do make my husband carry my bags every chance I get.

**Ken Sutcliffe:** There you go.

**Andi Sutcliffe:** There you go.

**Ken Sutcliffe:** Sounds like a good man.

**Mindy Henderson:** He's pretty good. He's pretty great. I'm going to keep him. So Ken, you served, like I said, both in the military and as a firefighter and of course on the search and rescue teams. And first of all, let me say thank you for your service. That's incredible. Can you tell us briefly about, I know that there's a lot potentially to unpack there and I think that you spent a number of years doing both things, but can you tell us a little bit about your experiences in the military and as a firefighter, what you did, where you went, how long you served, all of that?

**Ken Sutcliffe:** Yeah, I would be happy to. I joined the Army at age 17. My mother had to sign on the dotted line because if you're less than 18, you can't join the military without your parents' signature. I joined the Army in June of 1980. I went active duty in September of 1980, basic training at Fort Knox. I went in to be what was at the time called a Cav Scout or a Cavalry Scout. And essentially, your job was to go out ahead. Just like in the old days, you had to have scouts out front to figure out what's going on and what's happening and where the enemy is, so the job of the cavalry scout in the modern day Army in the '80s was to be out front of everybody else, find and fix the enemy's position and be able to report back and let them know where they were.

Did my basic training for about four months, graduated out of basic and my advanced training. I went overseas to Germany, spent two years in Germany with the second cavalry regiment. Our job there was to patrol the Czechoslovakian slash East German border. And so we would do border tours every four weeks or you would go up about every month, one week for a month, go up there and you would drive gun Jeeps along the border with Czechoslovakia, make sure the fence and everything was intact and whatever else.

After that, I was brought back to the United States, went to Fifth Infantry Division at Fort Polk, Louisiana. I scouted there for two years, attempted to get into helicopter flight school, which required me to extend for a year. Was unable to at that time based on just the needs of the Army, so I got out of the Army active duty after five years, went ahead and decided that I wanted to move on with something else, which was becoming a firefighter.

I went to college. I had to have 45 hours of college for Dallas Fire Department. Went ahead and got that accomplished and joined the Dallas Fire Department and tested for them in April of '87 and joined in June of '87 and spent 33 years working for Dallas Fire Department. I stayed as a firefighter, rode the tailboard or the back of the apparatus, put out fires, took care of car wrecks, went to paramedic school, rode the ambulance for 12 years, and then moved into the technical rescue aspect of the job. And I worked in the technical rescue aspect and search and rescue for the last probably 15 years of my career. And I retired in June of 2020 after 33 years on the fire department.

**Mindy Henderson:** Wow. And I've got to say, the irony is not lost on me, that you were out there filling the boot as a firefighter for MDA and little did you know that this was in your future. I mean, do you just do the V8 head slap?

**Ken Sutcliffe:** Oh, yeah. Oh yeah. You're like ... I did it for 33 years. I mean, we did it every year except for COVID near the last couple of years before I retired. With COVID and everything else, it stopped, but for at least 30 years, every spring we were out filling the boot, and of course with the fire department, it becomes a competition and it was to see what station, what shift could raise the most money for MDA. And so we worked. That was the big thing. And so everybody tried to push and our station, when I was working at Station 15, we became, I think two years in a row, we won, beat everybody in the city for collecting money.

**Mindy Henderson:** Wow.

**Ken Sutcliffe:** It's fun, and we enjoyed it, had a good time. You met people, you got to talk to them for a second at the lights, and you'd just go around and people would dump every bit of money they had, change, stuff like that.

**Mindy Henderson:** Amazing, amazing. It's fun you say, and I believe you. I'm sure that it's tons of fun. Also, I would guess hot because you hail from Texas, which is toasty. I'm also in Texas. And so do you just smolder in your uniforms the whole time?

**Ken Sutcliffe:** Yeah, so a lot of times we would end up collecting. You'd start out wearing bunker pants and a T-shirt, trying to make everybody, like, "Oh, it's the fireman," and then by midday you were down to pants, and then if you had shorts by the afternoon, you could change into your duty shorts, because it would get very, very hot out there, especially in the late spring, early summer.

**Mindy Henderson:** That's amazing. Well, as someone living with spinal muscular atrophy, again, I say thank you for all the years that you spent doing that. The amount of money the firefighters raise just blows my mind all the time.

Ken, I told you when we spoke last week that you have the energy of, and I haven't known you long, but it's impossible to miss, you just have the energy of a calm and solid leader. Does that come from your experience in the service and as a firefighter or has that always been who you are?

**Ken Sutcliffe:** Well-

**Andi Sutcliffe:** A combination of both [inaudible 00:14:18].

**Ken Sutcliffe:** A combination of all three probably. I mean, I just have been always able to, for whatever reason, be calm when everything around me is going a thousand miles an hour. I've always been able to be calm and be able to critically think. And the military I think I honed my skills there. And then on the fire ground, I mean, at first you're told

what you need to do, but then as you get more experience, you know what you need to do.

And then pretty soon as you get older, you fall into that teaching position where you're helping the younger guys learn, and so it gives you the ability to just lead. Even if you are not an officer, you are leading the younger guys, especially when you are a senior firefighter. And I always led by example. If I can do this, you can do this and let's get it done.

**Mindy Henderson:** Amazing, amazing. I'm going to shift gears a little bit now and talk about your diagnostic journey and how all of that has unfolded, but I suspect that that's a quality, the sort of calm tendencies and strength and leadership, I suspect they've come in handy in your newest sort of battle in life as someone living with ALS.

**Ken Sutcliffe:** It has. I mean, my diagnostic journey was ... I retired in June of '20. December of '20, I was out in the garage reaching up to get a cooler off the top shelf. And you don't ever think about it, you just reach up and get a cooler. So I reached up and grabbed a cooler, except my left arm didn't go all the way up. And I kind of was like, "Why?" It's like it stopped about three inches before my right arm.

So I told myself, "All right, left arm go up," and it went up like it should. And I was, "Oh, weird," and I didn't think much of it that day, but later on I started to get a little bit of twitching in my biceps and I was like, "Well, I need to take a nap, eat more potassium." They went away and finally I noticed that the left arm was becoming more ... not reaching up higher. And so I went to my regular doctor and they were like, "Well, let's go have a look at your left shoulder where it started." Went to that doctor. He did a series of tests, and it's a disease that essentially is diagnosed by ruling out everything else. There are tests that they use to help diagnose it. There is no definitive tests for ALS.

**Mindy Henderson:** And you shared with me that your particular occurrence of ALS is not genetic, correct?

**Ken Sutcliffe:** Correct. It is not. It is not genetic. No one in my family had a history of anything. My mother had Parkinson's and that's it.

**Mindy Henderson:** Okay. Okay. So can you tell me a little bit about what the progression has been like and how you're doing now?

**Ken Sutcliffe:** Sure. When I was diagnosed in November of '21, I had lost a lot of use of my arms, both of them, the left and the right. I could still use my hands normally, my lower arms, but I couldn't lift either arm up very well at all. Then I went from that point, the arms continued to get more and more weak, less useful. By the time I got into what the spring of '22, they really weren't working at all, right, babe, kind of?

**Andi Sutcliffe:** You could eat, but it was really ... I mean, it got to the point where he needed full assistance eventually, but you were still working at that point. He was an instructor across the country for Texas A&M teaching disasters in the community and-

**Mindy Henderson:** Oh, wow.

**Ken Sutcliffe:** Wide area search.

**Andi Sutcliffe:** Wide area search. He traveled all over the country and was still able to do it until finally got to that point where he just couldn't anymore. That was a hard day for him to give that up, especially being in the military, then firefighter, and then on the task force, and then teaching disasters, how to survive in a disaster in a community or for public servants, and then to not be able to do it anymore was really tough. It was a really hard day.

**Mindy Henderson:** I bet. I can [inaudible 00:19:15]. Yeah. And Andi, I have to imagine for you as well as Ken's wife, that it would be ... I mean, I don't want to put words in your mouth, but I suspect it would be such a helpless feeling to watch this unfold.

**Andi Sutcliffe:** It's devastating. And it hurts me because I've watched this strong man for the little bit of time that I've known him, although I feel like I've known him a lifetime, and heard about his accomplishments, seen his accomplishments, and then to see him go to sitting in a chair and being uncomfortable or not being able to move, not being able to do for himself, and he jokes about carrying my bags, but he literally would come and train with us just to come and be around me and Skye, my partner Skye, and would help carry stuff. And he always said one day that he felt like he would have to take care of me. God said, "Oh, no."

**Ken Sutcliffe:** That was the plan. That's the plan I had anyway.

**Andi Sutcliffe:** And so his little plane didn't work out as he thought it would. And so it's tough. It's tough to watch him knowing what he was, grieving the person that he was and grieving the person that he's going to be is what's [inaudible 00:20:30].

**Mindy Henderson:** Right, right. So Ken, are you ambulatory at this point?

**Ken Sutcliffe:** No. It moved from my arms down to my hips. Little did I know that ... I always thought you stood up with your legs, but evidently, you use far more hip muscles than [inaudible 00:20:48]-

**Mindy Henderson:** Oh, interesting.

**Ken Sutcliffe:** Yeah.

**Mindy Henderson:** Yeah. I wouldn't know.

**Ken Sutcliffe:** Yeah. And it started working on the hip muscles and pretty soon I could not ... It was always hard getting out of chairs. I could still walk, but it was kind of a weird gait that I had at the time. And I mean, eventually the legs started to become weaker and it just was silly to try to do anything like that anymore. Albeit, I was stubborn as a mule. I was going to try to stand and try to do this, but after about five falls, I figured it was probably time to give all that up.

So now at this point, I'm wheelchair-bound or I'm bed-bound. It just depends. I use a Hoyer lift to get me out of bed in the morning and put me in bed at night. I use the Hoyer lift to put me in the chair. I use the Hoyer lift to put me in my shower chair so I can take a shower, get wheeled into the shower and take a shower. So there's a lot of things that I have lost, but I also feel like there's things I've gained, and that is just a different perspective on what quality of life was. At one time I would've thought, "Oh, I don't want that. That's not a good quality of life," but I'm going to tell you what, it's not bad. I'm not going to complain because it's life, and that's the best part about it.

**Mindy Henderson:** Very well said. So well said. For people who are listening who may be going through any kind of neuromuscular condition, which is typically progressive, there could be people listening who are losing function and going through that themselves. You kind of went there a little bit. I loved your perspective shift, but is there any other advice you would give to people who are going through that and maybe struggling with the emotional aspect of it?

**Ken Sutcliffe:** It's not easy.

**Mindy Henderson:** Yeah.

**Ken Sutcliffe:** I'll say that. But I will say that you have two options. You can move forward and you can greet each day as it's a great day, or there are some folks who just curl up and can't face anything. And I feel absolutely horrible for those people, and I'm just the kind of person because of what I've done my whole life, it's like, "Okay, well, we have a challenge. How do we fix this? How do we mitigate it? How do we move forward? What do we do to face this challenge?" And I try to do that every day. Go ahead, babe.

**Andi Sutcliffe:** I was just going to say Mindy, one of the things that we've learned to lean on is family, friends, resources, MDA, networking groups, anything that you can join or be a part of, because like Ken said, that wasn't in the ALS handbook that we weren't given because everything is so different that you don't know what to expect. So learning from other people who've experienced it and everybody's experience is so totally different, but just leaning on those people to learn what you can learn and how to navigate the rough days, how to navigate the days where you need a little bit more equipment, the things that you don't think you need, you wait too long and all of a sudden it's too late. You need them five weeks prior.

And then family. Our family and friends are such a strong tribe and community for us. And Ken's firefighter buddies, they come over. They're here if you need anything. And I would say probably in the beginning, we didn't lean on anybody and you're like, "I'm



good. I'm good." You're not good. And I think if you keep it in, you're suffering in silence where you could be reaching out to get help, whether it's professional or family or friends or whatever other resources are available. It's paramount. You need it because that's what gets you through the tough days. It gets you through the good days.

But just giving up and letting go and letting other people help you I think is one of the most important things, and again, research. Start from the beginning, even though it's like, "Down the road, I won't need this for a while," right? When you need it, it's usually a little bit too late. And I think that's just part of the journey.

**Mindy Henderson:** Yeah, very good point. And there are a lot of things that could fall into the category of what you're talking about, but I will say durable medical equipment, post-COVID, the timelines for getting what you need in that area, it takes forever. And so you're 100% right in so many different ways, but I have to go there and say, start that process now.

**Andi Sutcliffe:** You do, honestly. Like I said, we learned the hard way that you wait and it's too late. I mean, it's just like the wheelchair. Ken never thought he'd be in a wheelchair, so we kind of pushed that off. And once we realized he was going to be in a wheelchair to get fitted for it, to wait for it to come in, like you said, all of it took time. And he actually should have been in the wheelchair sooner than we were able to get him into one, so lesson learned.

**Ken Sutcliffe:** Who knew they fitted you for wheelchairs?

**Mindy Henderson:** Sure.

**Ken Sutcliffe:** I mean, obviously I just thought, "I need a wheelchair," and one shows up.

**Mindy Henderson:** Right, exactly.

**Ken Sutcliffe:** Not the case [inaudible 00:26:34]-

**Mindy Henderson:** Or you order one off of Amazon or something.

**Ken Sutcliffe:** Yeah, yeah. Oh, my wheelchair's here. No, not that.

**Mindy Henderson:** Not how it works. Andi, you probably didn't expect to be in a caregiver role at this point in your life and in your marriage. What's life been like for you? What advice would you give to other partners or spouses out there again, who might be listening?

**Andi Sutcliffe:** I will say it's not easy and I don't pretend that it's easy. And again, that's when I lean on family and friends and support for whatever I need. But also, it is hard to sit and watch. So for me, it's just like the airplane. You have a child with you, you put on the mask first, so you have to take care of yourself first.

I see a therapist and it helps me get through the grieving process or processing things, which I couldn't on my own figure out. I thought I was strong and I could do it. I could do

the dog thing, I could do this. But that, it's a whole different beast. And so to be able to talk to somebody and help them work you through your issues is paramount, again.

It's just, like I said, I didn't think I'd ever have to be a caregiver, but I don't know how to explain it. It's kind of like my boys. It's like they fight to take the control of the wheelchair to help Ken. Everybody wants to help Ken. He's such a positive and good human being that you want to do for him. I love him, obviously, and there wouldn't be anything I wouldn't do for him.

He got out of the hospital last week for a short stint. I didn't leave his side because I wanted to make sure, because even the medical professionals, everybody, they don't always know what ALS entails. They know it's neuromuscular, but they don't realize the shoulders, you can't grab the shoulders or they'll sublux or just the little things that I had to be there, or even a Hoyer lift, putting on a sling.

You'd be surprised how many people in the medical profession don't know how to cross the legs, and literally he could fall right through. So I've learned to be a strong advocate for him and do my research so that I can protect him. It's just like mama bear. You have your children or people you love.

**Ken Sutcliffe:** [inaudible 00:28:48].

**Andi Sutcliffe:** I mean, you do. You step up and you're very protective and you're in that fierce protective mode, and you'll do whatever you can. And again, it's not what you expect, but one day I think I'll probably sit back and breathe for a minute, but until then, I'm here to fight for him and with him as long as we're in the fight.

**Mindy Henderson:** That's amazing. And I love that you noted that you're taking care of yourself too by going to therapy and all of that. And I think it's such an important point. Again, even if you feel like you're doing fine and you don't think that you need it, I think it's good to get ahead of it and maybe get it before you think you're going to need it.

**Andi Sutcliffe:** And you still have bad days. It's not going to solve the problem, but just to help navigate it and think through things and get help just to talk to somebody, because again-

**Ken Sutcliffe:** Remember the day I got diagnosed and that therapist came in?

**Andi Sutcliffe:** The therapist looked at me, he goes ... What'd he say? "You okay?"

**Ken Sutcliffe:** Yeah. He looked at me and he goes, "Are you okay?" And I said, "Yeah," kind of questioning, like, "Why would you even ask me that question after I'm being diagnosed?" Andi wasn't okay.

**Andi Sutcliffe:** He goes, "Are you okay?" I couldn't breathe. I couldn't talk. I literally could not get a word out of my mouth. And the ironic thing is Ken had me log into the portal for the medical professionals-

**Ken Sutcliffe:** For test results.

**Andi Sutcliffe:** ... for the test results. And so real time, I'm watching these tests come in, researching the tests to see what they mean. So I kind of knew and Ken, like he told them, he goes, "I'd be surprised if you told me I didn't have ALS." But again, there's no hard test that shows it, but all these other small tests that they do, I could tell that that's where we're headed. And just to have somebody say it, like I said, I literally could not breathe or get a word out of my mouth and just sat there and cried, and then again had to go home and process it.

**Mindy Henderson:** Sure.

**Andi Sutcliffe:** Nobody expects to hear that. I mean, Ken says he did, but I think still in some way it was probably a little bit of a shock to you.

**Ken Sutcliffe:** Yeah. I mean, it's a shock, and yeah, I'll say it this way. I would've been surprised to find out that I didn't have ALS, but when they say it still, it's still a gut punch.

**Mindy Henderson:** Yes.

**Ken Sutcliffe:** There's no doubt about it.

**Andi Sutcliffe:** Reality check.

**Ken Sutcliffe:** I mean, I may have thought that I had ALS, but you know what? There's still that tiny little bit of you [inaudible 00:31:25] maybe not.

**Mindy Henderson:** Well, and it's not real until someone says it out loud. So yeah, I totally get what you're saying. And I've had moments in my life where just the world around you kind of goes fuzzy and nothing feels real anymore, and you're just sitting in this state of shock.

**Andi Sutcliffe:** And see, you get it. You know. You understand. The thing is too also, I think people don't realize, even though you get that diagnosis and you're told this, for us, it's never quit. You don't quit just because you have that diagnosis. You keep pushing. And again, like MDA Fill the Boot or any other opportunity to fundraise, to get research, because that research is so important and valuable. It's just like any other disease. You don't know what one day, what one test, what \$1 is going to make a difference and find a cure.

**Mindy Henderson:** So true.

**Andi Sutcliffe:** So you hold out hope and never give up because if you give up, you're letting yourself down, your family down, and your community, the ALS community, because everybody is in the fight together. And so I think as long as you keep fighting, there's still that small bit of hope.

**Mindy Henderson:** Absolutely. And working for MDA, I see it firsthand. We write the blogs and the press releases and things when drug approvals happen, and it feels like such a floodgate has

been opened of medicines and therapies and things that are helping people with different conditions, ALS included. And it is becoming a much more frequent occurrence that we see things getting approved and into the hands of the people that need them. So absolutely, I think that it's easy for me to say and maybe harder to do when you're facing something like ALS, but I think there's every reason to hope.

**Ken Sutcliffe:** Oh, yeah.

**Andi Sutcliffe:** And that's the thing that's hard to do. I think a lot of people, like Ken mentioned, some of them just give up. They don't want to dive into the fact that they have ALS where for us and for Ken especially, Ken feels like this may not be his time to find or be a part of that cure, but if he can help somebody else, and same with us, we want to be able to be proactive and help people who are maybe just starting their journey with ALS to help fight the fight, because again, you don't know what the result's going to be and when it's going to be.

**Mindy Henderson:** It's true.

**Andi Sutcliffe:** We're going to do whatever we can until his last breaths to make sure that we can help fight along with everybody else to help find a cure for this horrible disease.

**Mindy Henderson:** You are amazing. I know. Yeah. Let's talk a little bit about what's been helpful to you. Again, this is, of course, it's different for everybody, but it's a relatively rapidly progressing illness, which means that your needs change rapidly as well. So what are the resources, the tools, things that you found helpful and impactful in making your life easier or in maintaining your independence?

**Ken Sutcliffe:** I think Andi will agree with me on this, and that was the first and most important thing is you've got to reach out to an organization and learn because you don't know what you don't know. So you start thinking you know what you're supposed to be doing, and you don't. They give you a diagnosis, but there's no handbook, as I joke.

**Mindy Henderson:** Wouldn't that be nice?

**Ken Sutcliffe:** Yeah. There's no handbook on steps you need to do. And so you need to reach out, find out, get the information, learn what's out there to help you learn what's out there to give you information and guide you. Those things are paramount. Wouldn't you agree, hun?

**Andi Sutcliffe:** Yeah, and utilize them. There's a lot of networking groups, and to be honest with you, that might not be the match for somebody. It might not be the thing to go. And to be perfectly honest with you, I follow a lot of groups on Facebook. Now, am I actively involved? Not necessarily, but I will take information from it and utilize that information. Doesn't mean you have to be a part of it. A lot of people share. I'm not one typically to get onto a site that I don't know somebody. But for this, again, we want to be as brutally honest as we can, again, to hopefully help somebody. And if it helps one person, that's a win.

**Ken Sutcliffe:** And I mean, new medications are out there. There's trials out there.

**Andi Sutcliffe:** Trials, yep.

**Ken Sutcliffe:** I mean, especially in the very beginning when you're first diagnosed, find out what trials are available to you because as this disease progresses, you become less eligible for trials.

**Mindy Henderson:** Right. That's a really good point. I'm glad you said that.

**Ken Sutcliffe:** Because you don't realize that until, "Oh yeah, no, yeah, sorry, you can't come in this trial because you can't move this or you can't do that," and so getting into that right off the bat is important.

**Andi Sutcliffe:** And I would say too, our doctor, we would hear about medications and present it to her and say, "What about this medicine?" They don't always offer it to you. And I don't know if that's just doctor to doctor, it's different. But also I know that if a doctor's has part of a study, they're more likely going to grab their patients. So you have to be proactive again and do your research, find out what studies are out there, and there's a national website or registry that you can go and look and see what studies are out there, and then reach out yourself because you have to be your very best advocate because again, doctors are going to take care of people in their hospital, their groups, and there might be one that you don't have to go in all the time or maybe one closer to you. So again, do your research and go to those registries and see what's available and then ask.

**Mindy Henderson:** Absolutely. And there are things happening now, wearable devices and all sorts of things that they're trying to do in the clinical trial world right now to make it easier for people to participate. And so yeah, I think that there's so much that could be a possibility, and we'll make sure in the show notes that we put the link to the clinical trials and things so that people can go take a look. Yeah. What about things like equipment or home modifications or electronics, anything that's been a game changer for you that you think-

**Ken Sutcliffe:** What would you think would be the biggest game changer?

**Andi Sutcliffe:** So again, you do your research and ask. So a couple things Ken's on. Obviously the muscle diaphragm are affected, so he does a cough assist, which helps strengthen his diaphragm. Reaching out to groups like I AM ALS and muscular dystrophy, all those places that can give you resources.

Another one that we've just gotten and that he's going to start working on is called an eye gaze. So he's going to start voice banking, which will literally be his own voice, should he lose his voice, which again, there's no guarantee, but again, this is one of those things that you need to get on right away.

**Ken Sutcliffe:** If you wait too late, you can't talk.

**Andi Sutcliffe:** Right. And so with a computer, he would be able to track with his eyes and it would talk using his voice. And again, that's something you might need, you might not need, but you don't want to wait because then the option may not be available to you. So that's one.

**Ken Sutcliffe:** Learning how to set your iPhones or your Android devices so that you can answer them with your voice and things like that or send texts just by using your voice. And those options are in both of them that allow you to flip switches that allow you to answer your phone by saying, "Hey Alexa, hey Siri," whatever.

**Andi Sutcliffe:** Because he's unable to use his hands, so just little things like that. One of the things that we learned from another ALS group, it's kind of cute. So their feet, the wheelchair pads are hard, so one of the patients was told by therapists to put those car wash mitts on it. And so the car wash mitt fits on each one, and it's padded and it's soft, so whether you're standing on it or not, you've got your feet resting so you don't get pressure sores. That's another thing is pressure sores, being able to have somebody who knows what to do or constantly moving, because once you get those pressure sores, that's a hard deal to get cleaned up. And obviously whether you're wheelchair bound or not, it can be debilitating-

**Ken Sutcliffe:** Very short period of time. It gets infected.

**Andi Sutcliffe:** Yeah. So again, stuff like that, the eyes, the padding, elbow pads. He has these little sherpa, like sheepskin. You can get bandages that cover the heel pads or elbows, but to rest on it, it's like sheep skin and we put it on him, Velcro them on, and it protects his elbows-

**Mindy Henderson:** Oh, brilliant.

**Andi Sutcliffe:** ... so he doesn't get pressure sores. Same with his heels. There's just a lot. Again, wheelchairs ask because Ken's upper body has become increasingly weaker. And so from side to side, his motion, so now we've got the wheelchair that wraps around on the side a little bit more to give him some more support, and waiting on a head one, a head rest that's a little bit different that wraps around to protect the side of his head so if we're in the car and he's jostling around, it'll help stabilize him more.

So the thing I would say about all that stuff is ask, "Okay, this is what I'm experiencing. What's available?" Tell them what your symptoms are, what you're going through. And they're going to go, "Oh, I've got a fix for that. Let's try this."

**Mindy Henderson:** Yeah, that car wash mitt thing is genius.

**Andi Sutcliffe:** Yes.

**Mindy Henderson:** I might steal that.

**Andi Sutcliffe:** And you know what? We lower his chair and let him clean the floors too.

**Ken Sutcliffe:** Yes. I drive around with my mitts and I dust the floors.

**Mindy Henderson:** I love it. Perfect.

**Andi Sutcliffe:** For comfort and ease, it's a great thing. It really is, so little things like that.

**Mindy Henderson:** Yeah, that's incredible. I'm going to go back just for one second to being a veteran and being a firefighter. And is it three times more likely that veterans and firefighters will develop ALS?

**Andi Sutcliffe:** Two to three times.

**Ken Sutcliffe:** Yeah, two to three times more likely than the regular.

**Andi Sutcliffe:** And both.

**Mindy Henderson:** Okay. So I asked you this question a week or two ago, and you gave such a beautiful answer. I'm going to ask it again. If you had known then what you know now, would you have changed your path?

**Ken Sutcliffe:** No. And that's the simple answer. But the longer answer is yeah, I mean, you're not going to not think about it, right, but here's the thing. I grew up wanting to be an Army man or a fireman, and I was blessed to do both in my life. I never had a job. I never worked. I was in the Army and I was on the fire department, and they were both ways of life, so I never had to ever ... I always was happy to go to work or to the job.

And I would also say that I was born to do this, so had I chose any other career path, I feel like I would've been miserable. So going back and looking back now, given my current state of affairs, I would've changed nothing because I had 40 years of doing things I loved as opposed to 40 years of mediocrity and being miserable, and I'm not saying everybody is miserable in their job. What I am saying, for me, I would've been not doing what I did.

**Mindy Henderson:** This was the path that was meant for you, it sounds like.

**Andi Sutcliffe:** And like he said, he never had to work a day in his life because he enjoyed everything he did and wouldn't trade it for anything. And everybody asks him, and his quick answer is, "No, I wouldn't change it."

**Mindy Henderson:** Well, and I want to ask you this too, because there may be people again out there who are considering a career as a firefighter or in the military and may pause because this information comes their way. But you also shared with me that in the world of firefighting, there are things, again, because people like you who are spreading awareness, there are things that fire stations and different people are doing to take precautions. Can you talk a little about that?

**Ken Sutcliffe:** Yeah. I can only speak to what Dallas has done, but when I joined the Dallas Fire Department, we used to say on the fire department, "Well, back then the smoke was thicker and the fire was hotter." It was a long coat, three-quarter boots. You had an air pack. But there were still guys who had fought fire that were working at the time that they didn't have air packs when they started, and they used sponges in their mouth and they'd breathe through a wet sponge to try to-

**Mindy Henderson:** Wow.

**Ken Sutcliffe:** Yeah. So nowadays the fire departments have become more aware of all kinds of possible diseases that have been associated with the job, ALS, of course, being number one of those. But they've gone to buying extra sets of firefighting gear, so each fireman will have two sets of firefighting gear, so on your shift, if you have a fire, you don't have to put the same wet, dirty, smoke-filled slash who knows what else filled from burning gear on. You put it on your fresh clean set and finish your shift. In the meantime, you throw your dirty set into what they call an extractor. It's like a giant ... I don't even know how to explain it.

**Andi Sutcliffe:** Washing machine.

**Ken Sutcliffe:** It's like a giant washing machine that's beyond super heavy duty. It's like comparing a shovel to an excavator when it comes to that stuff, and it washes everything. You bring it out and hang it to dry.

Some of the other things they do now is when I joined after a fire, you took your mask off, you overhauled in that smoky environment and cleaning out the burned rooms and stuff. Nowadays you're required to wear your mask at all times when you're inside the burning building. Even though it's not burning anymore, when you're inside overhauling, you're required to wear your mask.

**Mindy Henderson:** Sounds wise.

**Ken Sutcliffe:** Yeah, there are many things that are coming along in the fire service to mitigate possible issues down the road for firefighters.

**Mindy Henderson:** That's great. And I know you said you could only speak for Dallas, but even by sharing this on the podcast today, there may be people in New York who hear this and then they can go in and talk to their fire station about it and hopefully implement those same practices, so I think that's great.

**Ken Sutcliffe:** And I think thanks to the IAFF, International Association of Firefighters, I think that this has become nationwide now. They have spread the news through, well, when we filled the boot, you learn stuff and they've spread the news throughout their different locals that, "Hey, changes have to come," and they are for sure.

**Mindy Henderson:** Yes, absolutely. Gosh, I wish that I could talk to you guys all day long, but I have I think just one more question for you. Unfortunately, we all know the realities of ALS and



your incredible people who have clearly contributed so much to the world around you and the people you love. There are a lot of people who love you both. Ken, what do you want your legacy to be?

**Ken Sutcliffe:** I want my legacy to be somebody who handled this with grace and courage, and also was willing to take the time that he has left and bring awareness and bring hopefully other people who might think they don't have a chance to hear my voice and say, "You know what? You do have a chance. You do have a life," because the diagnosis, it's not over until it's over. And every day you open your eyes is a great day, and you have to move forward with faith, and you have to move forward with conviction, and I mean-

**Andi Sutcliffe:** Never give up.

**Ken Sutcliffe:** Never give up. And I just hope that that can show through me and in the time I have left, that I can bring awareness, do things, and hopefully one day they do find a cure for this disease and it is a thing of the past, or at least it's a thing that once you do get a diagnosis, it can be treated.

**Andi Sutcliffe:** And bringing awareness.

**Ken Sutcliffe:** Awareness. Yeah.

**Mindy Henderson:** Absolutely, which you guys are both doing brilliantly, and I know that there are a lot of people out there who you're helping and who you will help, people that you'll never meet, that you're going to change the world for. So thank you so much for being here. It's been such a pleasure talking to you, and I count you as new friends in my life, and I'm just so grateful to have had this conversation with you.

**Andi Sutcliffe:** Thank you for allowing us the opportunity too, because without being able to share this through podcasts or through other media resources or friends or whatever, the word's not going to get out. And I just think more opportunity, and like you said, somebody in another state might hear this and may change their life in one way or another, or they're willing to help in your journey.

**Mindy Henderson:** Absolutely. I think it will 100%. Well, thank-

**Ken Sutcliffe:** Thank you so much, Mindy.

**Mindy Henderson:** Thank you again.

**Andi Sutcliffe:** And bless you with your journey as well too.

**Mindy Henderson:** Thank you. You're so sweet. I appreciate that.

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Thanks everyone. Until next time, go be the light we all need in this world.