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Episode 7: Access to the World: Accessibility in Our Homes **November 18, 2021**

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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, [00:00:30] to inspire, and to entertain.

We are here shining a light on all that makes you 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. Welcome to my guest today, Paul Robertson. Paul is the founder and owner of Fishing For MD, and he's recently built a home [00:01:00] to meet his own accessibility needs and has agreed to join me today to discuss accessibility from a residential perspective.

Paul, I'm so excited to have you here today. I actually also built my own home with an eye to accessibility for my wheelchair, and I'm really excited to hear about your very recent building adventures.

Paul Robertson: Oh, that's great. Yeah. Thanks for having us on today, Mindy. I really appreciate it.

Mindy Henderson: Absolutely. Would you like to tell us a little bit [00:01:30] about yourself and your condition and how it affects your mobility, if you don't mind?

Paul Robertson: Sure. No problem at all. I live in Maryland. I'm in my early fifties. I noticed about 20 years ago that I was having some issues going on with my legs and so forth, with mobility and starting to trip, slip, and fall a little bit, and a few problems. Anyhow, as time progressed... I am a father of four. I was an athletic coach with

kids. [00:02:00] Grew up in Maryland. Always around boating and fishing my whole life.

As time went on, I had a successful business that I ran. I still own the business today. I have a team of people who are running the business so I can spend the majority of my time within Fishing For MD.

Mindy Henderson: Nice.

Paul Robertson: Anyhow, basically what happened to me was I decided, after a pretty bad fall, one of many, I have limb-girdle muscular dystrophy type 2J, which really affects your quads, [00:02:30] hips, and then you're starting to affect the shoulders and your upper arms, the trunk muscles of your body, a deterioration of muscle fibers and obviously strength. Then that leads to flexibility issues and other things as well.

But yeah, to give you just a real short story on how Fishing For MD started, I had planned to put together a professional, competitive offshore fishing team prior to really finding out how bad this muscular [00:03:00] dystrophy was. I ended up putting that business plan on the shelf and I had shared it with a business advisor. I spoke to him about six years ago after taking a really bad fall. He said, "How's everybody doing? How's the family? How's the business and everything?" Of course, I'm "Good, good, good. Everything's good."

He says, "How are you doing?" And I said, "I'm really not doing well at all." I said, "I took another fall on my way to work and I lost it." You have one of those or maybe more of a one of those moments in life where you just hit bottom.

Mindy Henderson: Sure.

Paul Robertson: I hit bottom, [00:03:30] and I just said, "I'm done. I don't want to do anything anymore. I'm finished." He said to me, he said, "What did you ever do with that competitive offshore fishing team that you wanted to start?" I said, "Well, I put that business plan on the shelf. I've been busy coaching kids and my business, and family, and friends." He just said, "Have I ever hung the phone up on you?" I said, "No. What was that all about?"

This is a guy I look up to and I respect. And he said, "Dreams expire." And all I heard was a dial tone. I'm like, "Wow." That was like, "What [00:04:00] the heck just happened here?"

Mindy Henderson: Wow.

Paul Robertson: Long story short, I ended up writing a letter, about three or four days later, to the CEO of the MDA. I said, "Hey, I have this business plan, this idea to do a fishing team, put change in the spin on it now. What I'd like to do is, for lack of a better word, have your endorsement to go out and build this team and a co-brand with MDA, where we could generate an opportunity to raise funds and awareness for those affected with muscular dystrophy and help support the Muscular Dystrophy Association."

[00:04:30] That's what we've done over the last five or six years. We've been very fortunate to use the branding of the team and the events and the tournaments that we go to and our [inaudible 00:04:40] and boats and all the different things that we do and parlay that into different fundraising events. We've created a pretty large awareness for muscular dystrophy in the boating and fishing community, which a lot of people don't realize. Boating and fishing from an economic standpoint, out in the marketplace is larger than golf and tennis combined.

Mindy Henderson: [00:05:00] Oh, wow.

Paul Robertson: It's a huge demographic market out there, billions of dollars a year. And we've been able to go out and create that awareness within the fishing community and boating community, about muscular dystrophy, where a lot of people never really put a lot of attention or thought a lot about muscular dystrophy. That's allowed us to parlay that into hosting. I've hosted four galas for the Muscular Dystrophy Association, which has raised about \$2.1 million.

We do a boat raffle and giveaway [00:05:30] a boat. Now we're giving away a truck and a golf cart every year. We're on our fifth one right now. At the end of the day, that's generating six figures and funding back to the Muscular Dystrophy Association from our organization. That was really my goal, was to be a million-dollar donor or fundraiser for muscular dystrophy. Some of it, we donate. Some of it, I do events with MDA, like the gala and so forth, and through my colleagues and associates, generate events.

That's where we are and what we've done. We've reached a lot of families, met [00:06:00] a lot of friends. Just super excited to be out living our dream and doing what we like to do, boating and fishing and fighting a good cause that can come out of it, with good results. That's a little bit about me.

Mindy Henderson: Yeah, no, that is fantastic. Congratulations on all of the success. I think, honestly, any time you're going through something hard, we've all got adversity and struggles that we go through. I [00:06:30] think that having a purpose is something that can really turn things around for you and get you into a different mindset. So I'm clapping my hands. You can't see me, but I'm high-fiving you and clapping my hands for you.

Paul Robertson: Well, thank you. Thank you. We really appreciate it. We've met so many people affected with muscular dystrophy. It's just amazing how many people come up to us at the marinas and the tournaments and when we're towing the boat and trailers up [00:07:00] and down the highway, and we stop at the truck stops and they come [inaudible 00:07:03], "My mom, my cousin, my aunt, my son, my friend, has muscular dystrophy." We've really touched a lot of people.

I have a soft spot for the kids with muscular dystrophy. So I have probably about 15 or 20 kids that I've really developed a special bond and friendship with them and their families across the country. We try and send them our shirts and stickers and hats and stay in touch with them. It's been good. It's been a [00:07:30] great outreach opportunity to build awareness for muscular

dystrophy. We've found ways to turn it into fund raising, which is a lot of things that, as we know, make the opportunity to go out and have kids' summer camp.

That's what we try and fund with, a lot of the stuff that we do, and obviously research and grants and treatments and so forth.

Mindy Henderson: Well, you've got a generous spirit and you're absolutely right. There's so many people out there who are affected by neuromuscular disease. And so, again, I just commend you for all [00:08:00] you've done.

Paul Robertson: Well, thank you. Thank you.

Mindy Henderson: Absolutely. Let's talk about accessibility in architecture in this house that you built. You built a home recently from the ground up, correct?

Paul Robertson: We did. I live right outside of the DC Baltimore area, but we've always had a home on the Chesapeake Bay, which became really difficult to navigate. It was a second home. We actually just recently sold it. My summer roots as a child, in my younger days, [00:08:30] was in Ocean City, Maryland, on the coast of Maryland, right on the ocean. We have a family house here, and the last four or five years, we've done a lot of events out of this area.

I was staying here at the family house that we grew up in, and it just became more and more strenuous for me to navigate, a lot of stairs, a lot of steps, bathtubs, showers, et cetera, low toilets, all different kinds of things. Finally, it just got to the point that I was talking with my family and I [00:09:00] just said, "We're going to have to do something different because I can't navigate this house."

I actually went into this mindset that I needed to go into a condo. "I've got to go to a condo and I could park underneath and get in the elevator and go straight up. But life will be great." Well, I thought that was going to happen. We looked at some different condos and found some stuff that we thought would work. One of the deals fell through. I was talking to a friend of mine who actually ended up building this new house and he's also a boat owner and fisherman and everything else.

I was having dinner with he and [00:09:30] his wife one night, and I was complaining about this deal that fell through on the condo. He's a home builder by trade. He said to me, he said, "Why don't you just find a lot, let me build a house that works for you?" I think three days later, we bought one of the last seven or eight waterfront lots in Ocean City, Maryland. My wife and I and the kids embarked on, "Let's build a house."

We went from having a family house that was hard to navigate, to thinking it was a condo, to then, "Let's build a house." That [00:10:00] obviously then opened up the whole discussion, "Well, what do we need out of a house? What are the things that we need and how does a house work for Paul?" And so, that's how we got where we were. Then we hired an architect.

Mindy Henderson: I want to stop you right there and ask you about your builder and your architect. It sounds like you had a friend. I don't know if that friend ended up being your builder, or if you had to go on a quest to find someone.

Paul Robertson: He ended up being the [00:10:30] builder, and-

Mindy Henderson: Okay.

Paul Robertson: ... which really, really worked out well. He's built about 10,000 houses all over the Eastern seaboard. So he's very involved. They've done big developments. They've done [inaudible 00:10:44], and so forth. The interesting thing, we had the builder and we had his on-site superintendent. Then we hired an architect. That was a challenge a little bit in itself too, because... I think a lot of people with muscular dystrophy can probably [00:11:00] relate to this. There's no one thing that helps us navigate, move better, prevent falls, slips, trips. We're all a little different with how this disease affects us.

Like for example, if I fall, naturally, everybody runs. They really want to grab your arm and pick you up. And I'm like, "No, doesn't work that way." They're like, "No, no, no, just give me your hand and I'll pull you up." I'm like, "No, no, no, we don't move that way."

Mindy Henderson: Right.

Paul Robertson: I think that when you first have that conversation [00:11:30] with a builder or an architect, they naturally just think to themselves, "Oh yeah, I got it. No problem. We'll put a grab bar here or a handle here and you'll be good." But once they really get to know... And that was the fortunate thing for me. I spent a lot of time while they were building the house here and we made modifications along the way. Some things we just said, "Hey, we're going to figure these out while we're building, because we're not sure what height to put things," and a lot of trial by error. You just had to get in there and figure [00:12:00] it out.

Mindy Henderson: Right. Let me ask you this. It sounds like you had an inner road because of your builder friend. There are probably people out there who don't know builders, don't know architects. And so, before we get into the actual building and how you made this home accessible for yourself, let's talk a little bit about the journey to find a builder and or an architect. What would be your advice there for [00:12:30] someone who's listening, who's got the same kind of accessibility needs as you and me, but maybe have never worked with a builder or an architect before, and don't know how to look for the right one.

Paul Robertson: Yeah. I think, obviously, referral and word of mouth is usually, in my world, is always the best. I mean, if you can get a referral, that's the best thing. I think, at the end of the day, I feel like the builder that we had really cared. If you could find someone that really cares about you and will listen to you, and not just make [00:13:00] it feel like it's just another house, I think that's really important. How you go about that, there's thousands of builders out there, no doubt.

Obviously, in the last two years, it's been... Or really last year, the supply chain issues have been a big deal. We were just on the front end of that, but I can see where that could have been a real problem with a lot of people had they been a little bit later. But I think, at the end of the day, working with a reputable builder, sitting down, [00:13:30] talking with them, they almost need to get to realize that this is going to be a special, different kind of a home that you're going to either renovate or build, depending upon what you do. Sometimes I wonder if it's easier just to renovate something than to build it from the ground up, but-

Mindy Henderson: Right. Probably pluses and minuses to both.

Paul Robertson: Yeah. It depends. I mean, budgets come into play and things are built different. I think at the end of the day, it's word of mouth. I think it's almost like you want, [00:14:00] even though our builder's done all of this stuff, he's done it over many, many years, he was only doing, I would say, a handful of what I will call custom homes. He was doing a lot of the production, the big builder homes, going in and building homes for the big national names that we know.

But I think that you don't want someone that's just trying to churn out quantity of homes. I think you really need a specialty builder, and you need somebody that's going to take the time to understand that you're going to need some special accommodations.

Mindy Henderson: [00:14:30] I'll say that when we found our builder, this was years ago, but we approached it problem by problem, which it sounds like you did too. I had a list of non-negotiables that I personally needed, like how wide I needed my doors to be, what I needed my light switches to be, those sorts of things. When we went in and spoke to the builder for the first time, we went through all of those things [00:15:00] to make sure that they were things that they could accommodate and get creative about. Was your approach similar?

Paul Robertson: For some of the things, it was, and obviously, some of the things, we learned and added in later. But I think, definitely, one of the things that we just talk about constantly, we have a lot of outdoor deck space on multiple levels. I've said, "I can't have a step down or a step up on the deck." There was a whole conversation about water flashing and water penetration. How do you keep the water [00:15:30] out if you have...

Yeah, usually, like my primary residence outside of DC, when you step out of the deck, you step down two or three inches, and that's designed naturally to keep water penetration out of the house. That was an early on conversation that we had, and they had to really figure out how they were going to do that. I'm not in a wheelchair. I do walk with a cane. I do have a mobility scooter if I go to events, or if I went to a mall, or if I went to a football game or a concert [00:16:00] or whatever it may be. Or if I'm traveling, I'll take that with me.

I'm upright mobile, but I'm not mobile without a cane or without holding onto someone's shoulder. My balance is a little off. Just that little step to step in is problematic. I wanted to be able to walk outside, if I wanted to hold a plate in

one hand and my cane in the other and walk in from the grill, I wanted to be able to do that. I can't do that in my other-

Mindy Henderson: Sure.

Paul Robertson: In my name outside of the DC area.

Mindy Henderson: Yeah.

Paul Robertson: [00:16:30] There were some things like that, like you said, non-negotiables that you just had to do. We can get into the construction and some things that I did, but the grade issues, we're at the beach, so we're at elevation zero, I call it. Not zero, but we're flat near the ocean, I would say. There was just some things related to the grade of the driveway and perimeter of the house. Everybody kept saying, "It's too flat. You can't do it." I said, "Well, we've got to figure out a way. It has to be flat."

Mindy Henderson: Yeah. Well, and that's [00:17:00] the thing. I think that you have to be really comfortable and get into a mindset of knowing that you're going to need to advocate for yourself and be a little bit assertive because builders have codes, and standards, and things that they're held to. But what I found was that if you push them a little bit, they can get creative and figure out how to solve those problems.

Paul Robertson: Yeah. When they dug the foundation and they do what they call the wall check, where they have the inspector from the [00:17:30] city or the town coming, before they pour the flat slab, he came and he said, "That's absolutely not right." And they said, "No, it's right per the plans that were submitted." He goes, "It's impossible. You can't do anything like that." And so, lo and behold, they made me fire an engineer and come back a second time, re-shoot all of our elevation grades, and prove to them it was right, because they just hadn't seen it before. It was something new.

Mindy Henderson: Exactly.

Paul Robertson: You had to go through that. It was frustrating at the time because you knew you were right. You [00:18:00] had to go prove it to the inspectors. But-

Mindy Henderson: Of course. But I think, to your earlier point, if you find someone who, when you're interviewing people, who strikes you as compassionate and creative and all of that, I think, usually, these things can be worked out, right?

Paul Robertson: Absolutely. Our builder was great. I mean, I never was really told, "Well, you can't do that. It was like, "Let's figure out how to do it."

Mindy Henderson: I love that.

Paul Robertson: I think that's a [00:18:30] good mindset to go in with a builder. If you're interviewing the builder, you're talking to a builder, I think you could ask questions like, what obstacles were you up against in one of your prior homes

where an owner said they have to have something done a certain way and everybody scratched their head and initially said, "That's not how you do it," or, "You can't do it," and then you ended up doing it that way. How did you do that?

Us who are living with disabilities, you'd never realize, I guess... People without disabilities, they always realize you have a disability. But like I said earlier, [00:19:00] they don't realize everybody's disability is a little different and it affects you differently and how you get up off the floor, if you can.

Mindy Henderson: The little subtleties of daily life-

Paul Robertson: Exactly.

Mindy Henderson: ... can really be different. Would you mind, I'd love to hear more about what you actually did within your house, some of the specifics that you did to make it accessible for you. I know you mentioned-

Paul Robertson: Sure.

Mindy Henderson: ... the decks and making sure that those thresholds were flat. What other sorts of things [00:19:30] did you do?

Paul Robertson: Well, it really started from like when you show up to the house, I can do a walkthrough from there. One of the things that we did was we did... I say, if you can picture a beach house on stilts. A lot of people have seen those in the outer bank. You see this house and it's stilts and it's open underneath, our house is like that. It's a two-storey house, but it's 10 feet off the ground. What I did was, on the ground level, it's all enclosed as part of the house. So the entire lower [00:20:00] level is all garage.

Mindy Henderson: Okay.

Paul Robertson: What I wanted to be able to do was a couple of things. I wanted to have a concrete floor, which I had a special coating put on that has some grip resistance to it because, obviously floor gets wet, slips, trips and everything else. So I had a professional coating done all the floor where it has grip resistance where I literally can pull my car into the driveway, I can open my door, get out of my car. And within about six feet of the car door is the elevator. I have an elevator-

Mindy Henderson: Oh, great.

Paul Robertson: ... that takes me [00:20:30] up. When we designed the house with the architect, everything was built around the location of the elevator. Whereas most people design a house and then say, "Where can I put an elevator?" For us, it was the exact opposite.

Mindy Henderson: [crosstalk 00:20:43] okay. That's a good tip.

Paul Robertson: Yeah. I wanted to pull in on the right side of the garage, so when I got out of the driver door, the elevator was there. I didn't want it the other way around. That was my beginning. The other thing, a lot of driveways and garages have a little

lip, like a one-inch lip from [00:21:00] where the concrete's a little higher. I was adamant I wanted that flat.

Mindy Henderson: I did the same thing in my house. Yeah.

Paul Robertson: Flat, straightened. I was challenged a little bit with the builder on that, because he was like, "Well, you need it elevated to keep the water out." I said, "Well, then we need a better seal on the bottom of the door," back and forth. We put a little eyebrow roof over the garage doors so that the rain didn't get up against the doors as much. That was one of the things that we did.

And then I was really focused on a flat garage and very [00:21:30] minimal incline in our driveway. That was one thing that I did, and then I had the elevator. So then, some other things that we did during the construction process, I put wood blocking in the walls everywhere. So there's extra wood all throughout the house at different elevations. My thought process all was, I had pulled so many handrails and [inaudible 00:21:52] bars and all kinds of stuff off the wall in my years of living with this disability. There was nothing I was going to pull [00:22:00] out of the wall in this house.

Mindy Henderson: Yeah. Okay.

Paul Robertson: Then I have video and pictures of where all of that is, so that if I come back and say, "I want to put a handrail on this wall, for when you're walking down the hall or whatever it may be, it's not just find the studs and, "Can you make it work?" There's full wood blocking in the wall. So that was really important, obviously, especially in the bathrooms and everything else.

Mindy Henderson: So smart. So it's wood blocking that you can't see, but it's in there in case you need to install a handrail.

Paul Robertson: Right. If you can [00:22:30] visualize, before you put drywall or installation on a wall, just the wood studs that are in a wall, then there's wood in between each stud. Basically, what I did was I took from, I think it was 28 to 40 inches high and made these wood sections inside, in between the wooden studs. Sounds like a lot, and it sounds like-

Mindy Henderson: No.

Paul Robertson: When you do a lot of this stuff, I think a lot of people are like, "Oh." They see dollar signs, more money, more money, more money.

Mindy Henderson: [00:23:00] No. It's so smart though to think ahead that way.

Paul Robertson: Even if you just did it in a bathroom. Obviously we did that and I could talk a little bit about my shower and bathroom and toilets and all that.

Mindy Henderson: Yeah.

Paul Robertson: But putting all of that in. That was one of the things that we did. I had designed where all of the toilets were going to be elevated. So for me, it's real challenging

to get up off of a toilet unless I have something to push on and lean on. So one of the things that I originally did was I designed [00:23:30] like a six-inch box on the floor, for lack of a better word, where the floor where the toilet was would be higher than the regular bathroom floor. Even though you can buy what I call an ADA toilet, they're still low, to me.

Mindy Henderson: Right.

Paul Robertson: Ironically, when we went and did our appliance selection at Ferguson Enterprise, a big national company, we were walking out of the showroom and my wife said, "Look at this toilet." It was literally right by the front door. I don't know how tall it was, but it's pretty darn tall. [00:24:00] Yeah. I think one of my kids said, "My feet don't touch the ground."

Mindy Henderson: Wow.

Paul Robertson: We got these really tall toilets. That was something that I didn't have to build that box on the floor. But those were ideas that were going through my mind, how can I get off this toilet? What I did, I made sure we have a bathroom in the garage and then we have a bathroom, a couple on the second floor of the bedrooms, and then the living area upstairs, our bedroom and so forth.

I made sure that our bedroom, and then one on the second floor, and one on the ground all had those three toilets. So wherever, [00:24:30] if I need to use the restroom on any floor of the living space, I have the ability to use a tall toilet. So that was-

Mindy Henderson: That's fantastic.

Paul Robertson: That was a big deal.

Mindy Henderson: Yeah.

Paul Robertson: And then, having the wood blocking in the walls allowed us to put the hand rails up. I was surprised. You think of hand rails and you think of you go in a commercial public bathroom and you see this silver hand rail, and I've got them. You have to have them installed before. Just looks like sterile, kind of hospital, kind [00:25:00] of industrial.

Mindy Henderson: Yeah.

Paul Robertson: I was surprised that the... I call them decorative grab bars and handrails, that you can buy. It's a few dollars more, but it's not ridiculously a lot more, and they look like they belong. They don't look like it was an after fact that somebody-

Mindy Henderson: That's so nice.

Paul Robertson: ... said we need to put on. So for me, that was a big thing. I didn't want this house to scream disability. I guess that's the right word. I wanted it to be built in and be a natural... There's six of us that live here. I'm the only one who has a disability. [00:25:30] I didn't want it to be like, "Oh, this is built just for Paul."

Mindy Henderson: Right.

Paul Robertson: I wanted it to look like a family house. That was really important to me.

Mindy Henderson: That was important to me too. I told my builder that I wanted the house to be completely accessible, but I didn't want it to look like it was built to be accessible. And they did a great job.

Paul Robertson: Yeah. Yeah. That goes back to your communication with the builder and designer. I'm a very hands-on person, so I was really involved a lot with it, making sure things were right. One of the [00:26:00] things that we did in our master shower, I wanted a walk in shower.

Mindy Henderson: All right.

Paul Robertson: Where you can just walk into it. I've stayed in so many hotel rooms and I'll request an ADA room. I was just in one recently at a fishing tournament we were doing. I said, "This is great that it's ADA, but when you get out of the shower, the entire floor, by the toilet, everything is covered.

Mindy Henderson: It's a swamp.

Paul Robertson: They call it a roll-in. I'm like, "It's a roll-in ADA, but it's the whole room is now wet."

Mindy Henderson: Yep. Exactly.

Paul Robertson: [00:26:30] I did about a half inch threshold, which, again was a point of discussion with everybody, and made sure that when we did our tile, we selected a tile that had good grip. There's different grip on tile for flooring and showers, and I wanted something that had a lot of grip, that when you were standing on it, if it was really wet for me, it would still be an issue. I'd probably slip and slide. And if you start slipping or sliding, you're probably going to go down in my condition.

[00:27:00] But I got a tile that has pretty good grip, so that it helps to avoid that. You talked about 36-inch doors. I made sure, even though I'm not in a wheelchair today, I made sure that my shower had a 36-inch door that swung all the way open.

Mindy Henderson: Yeah. That's such a great point about... I mean, I know this is the second time you've mentioned that kind of thinking ahead, but I think it's so smart that you did that and you thought about, "What's it going to look like in 10, 20 years?"

Paul Robertson: Right. Right. We oversized [00:27:30] our shower a little bit. We built a built-in bench, so there's a bench. Naturally, I think a bench is normally like 18 to 20 inches. Well, this one's 24. Yeah. Everything to me was, "Get it up. Get it a little higher." So we have that in there. Then we have a handheld device in there, and then we have the regular shower head. Again, those decorative grab bars that

are in there. They're all dark brown and not that screaming, industrial silver, whatever it is.

Mindy Henderson: Right.

Paul Robertson: It just makes it look [00:28:00] a lot nicer, I think.

Mindy Henderson: Yes.

Paul Robertson: And then, it doesn't scream... Yeah, even for your own psyche, because us people that are living with disabilities, obviously, you don't want every time you go to do something, just in the back of your head, go, "Oh, well, I can't do this the right way," Or not the right way, but the way normal people, or whatever.

Mindy Henderson: Yeah.

Paul Robertson: Yeah. So if you soften it up a little bit, then when you're using those devices, whether they're grab bars or whether they're the specific handle I put on the shower door so that [00:28:30] I can close the glass shower door when I'm standing there and not have to reach out and slip or trip or fall, that was important. I think those little things, it doesn't scream then that, "Oh, I'm doing this because I have a disability." I think it's good for your mental state and so forth.

Mindy Henderson: I agree. Yeah. There would definitely be a psychological impact to that, to have it in your face all the time, that you need special accommodations.

Paul Robertson: Right. Right. When [00:29:00] we did our shower, I made sure that we built in really good size wall niches. It's where they were notched into the wall for putting your shampoos or your soaps or whatever it may be. Because I just find that, put your grab bars, all what you're going to grab and don't put anything else on the wall if you can help it, that you're going to grab that's not supposed to be grabbed, because if you do take a little slip or... You don't want to be grabbing a soap dish, you don't want to be grabbing a washcloth holder or whatever it may be. Just to get [00:29:30] that stuff in the niches.

If you do have to grab something real quick, naturally, you're going to grab the first thing you see. Make sure whatever you're grabbing is going to hold.

Mindy Henderson: Right.

Paul Robertson: Again, I go back to me. I've ripped so many things out of walls over the years that you have to be careful. That was in our master bath we did that. The other thing, all of our bathroom vanities, again, I'm not in a chair. So again, it's a little different for some people, but they're all I think they call it bachelor height is what the building terminology is. [00:30:00] They're a little taller. So for me, to lean over, with weak quads and all, lean over to a low counter is more challenging. So everything, for us is, is like counter height, if you want to think of it that way.

Mindy Henderson: I did that also. We've got two vanities in our master bath, one is higher for my husband, one is lower for me. And the one for me also has clearance. We took the cabinets out from underneath so I can drive up underneath it.

Paul Robertson: Right. Right.

Mindy Henderson: Yeah.

Paul Robertson: Absolutely. Those are things to [00:30:30] think about. The other thing I did, it sounds crazy, but we had a set of cabinets in the master bath and I said, "I want to have a seat there."

Mindy Henderson: Oh.

Paul Robertson: They're like, "What do you mean?" So I have a built-in seat. Teak is a big wood product that's used on boats.

Mindy Henderson: Right.

Paul Robertson: I said, "I want a teak seat, a teak wooden seat that I can sit on, literally, just to put my underwear on and get things going." So that was just a little something. But when I built that seat, I had to accommodate a [00:31:00] taller set of cabinets next to it, so I could put my hand on and push and lean and get myself up, even though it was built up higher. So little things like that are all the things that we went through with the builder.

But that in the bathroom, it was just a big deal. The non-slip tile, the wood blocking in the walls, making sure we had a wide entry into the shower, a low threshold that wouldn't get water out onto the floor, tall toilets, those were all things... Our bathroom is just like our kitchen, [00:31:30] are two areas that we spent a lot of time in. Typically, at least where we are in our geographical area, the floors on those tend to be harder too. So they're not carpeted, normally.

So if you do fall, you're falling on a harder surface. That's the one thing I've learned over the years. I think that falling becomes really the scariest thing, for me, at least. I've dealt with a lot of challenges and I can't navigate this, or I can't get in here, I can't do that, or I can't climb these stairs. But the falls, [00:32:00] and I've taken a fair number of them, that's really probably the scariest thing, because I've had some instances where you do fall. And if you're alone, you might not get up for a while.

Mindy Henderson: Right.

Paul Robertson: You might wait for help or whatever it may be. Again, back to the flooring, that's usually our hardest floor. So you've got to think about that, "How are you going to protect yourself?" Those are some of the things that I did.

Mindy Henderson: Yeah. I mean, it sounds like you were incredibly thorough. But is there anything that you would do differently next [00:32:30] time, that you learned this time around?

Paul Robertson: It's funny. People have brought that up to us and they've come and they've looked at the house. Again, very fortunate, where I am in my career. I'm pushing into my middle fifties. I've had a successful business. So we'd built this as our... I hate to use the word retirement home because I feel like I'm too young to retire, but we built this as our last hurrah, if you would. So I think, at the end of the day, I really... I don't mean to say hit it out of the [00:33:00] park with what we did, but we really covered a lot of things.

We've only been moved in for a couple of months, so we're still getting our arms around everything, obviously. But for the most part, again, for my disability, with the way that I'm functioning, it's been pretty much spot on. So I'm really, really happy with that.

Mindy Henderson: That's so great. Honestly, I think one thing that I would encourage people to do is [00:33:30] if they're about to start building a home or working with a builder, wherever you're living right now, I might keep a notebook with me for a day and write down, from the time I wake up in the morning, what struggles there are, what challenges there are, what problems I need to solve and take that into the builder.

Paul Robertson: Right. Right. It's funny. One of the things that we learned... Again, this is a vacation home, but it's intended to be permanent [00:34:00] home as we transition. In the suburban home that we have at home, you have these grandiose master bedroom suites. That's what all the national builders, that's where we were, development and everything else they build. I think I had like 42 steps or something crazy to the toilet, from the house. Now I have about five.

Mindy Henderson: Oh my gosh. That's so great.

Paul Robertson: It's amazing. As you get older, you need less.

Mindy Henderson: Yes.

Paul Robertson: From when you're young, you're like, "I need all of this. I need the big..." Yeah.

Mindy Henderson: [00:34:30] Exactly.

Paul Robertson: Little things like that. Like in our kitchen, we did... For me, it was really important to have good accessibility in the kitchen. One of the things that really, really jumps out when you walk in our kitchen is we have a double oven on the wall, and the top of it has a French door oven. People look at it and they go, "That's really cool looking. I haven't seen that." Let me tell you why we did it.

The reason we did it is, again, [00:35:00] if you've got a disability and you struggle with balance or being upright or strength with your arms, whatever, it may be, try leaning over a hot oven door that's folded down and taking something out of the oven. But with the French doors, you literally open it up and you can walk right up to the oven.

Mindy Henderson: Wow.

Paul Robertson: Or stand right next to the oven. Or you could roll right up to the oven and you're in a chair. When you take that pan out of the oven, you're not leaning over that door.

Mindy Henderson: [inaudible 00:35:26] have known that such a thing existed.

Paul Robertson: Yeah. [00:35:30] It's pretty neat. It's just two doors. It's like two double doors, like two patio doors, French doors, if you think of it. You grab one handle and they both open up, and then you can get right to it.

Mindy Henderson: Incredible.

Paul Robertson: That was the stuff that we did there. And then, all of our kitchen cabinets, the lower portion of the cabinets are all big, deep drawers. We didn't do the typical cabinet where you open the door, you've got to stand in front of it, open the door, you've got to step back away from it. Then you've got to get down low and you've got to reach in and pull out what you need. These are all drawers. [00:36:00] So you can literally come right up next to it, have the drawer open, then you have accessibility to grab whatever you want.

Mindy Henderson: Amazing.

Paul Robertson: Yeah. I would encourage anybody who's doing a kitchen remodel or trying to make their kitchen more functional, if they've got a disability, think about doing all drawers. Some of these are big and deep. They're, I don't know, 12, 18 inches deep. It's not just like a silverware drawer. It's a drawer you could put your pots or your pans or anything else. That was something that we did.

Then we had our kitchen table, which serves as our dining [00:36:30] table, is the same height as the kitchen counter island.

Mindy Henderson: Oh, okay.

Paul Robertson: For us, everything... Again, it's like the toilet. Get up higher where you don't have to force yourself to get up. When you sit down, you don't have to drop as low. And all of our chairs for our stools, for lack of a better word, are all a tall seat which allows the ability not to have to use much force to get up and down. At first, you think, "Ah, I don't know. How's that going to look next to the island?" Yeah. You're going to have this island. I don't know if it's 30, I can't remember, whatever [00:37:00] inches.

You have a table at the same height. Again, you don't normally see that. You normally see tables lower than the height of the island. But from a functionality standpoint, the usability, that was something that we made sure we did in the kitchen.

Mindy Henderson: Right. There's so many different looks and styles to furniture that you can find someone... Even though the height may be a little unusual, I'm sure you found something that looks really nice.

Paul Robertson: Yeah. Sometimes it's tough to get that. We had someone make a table for [00:37:30] us. We picked out a piece of wood and they made the table for us.

Mindy Henderson: Wow.

Paul Robertson: Lead times took a while, but of course that's the whole world's been that way for a year. To get anything takes forever.

Mindy Henderson: That's true.

Paul Robertson: We just got our sofas the other day for the family room, and same thing with those. When we picked those out, what was the most important thing was the height, height and firmness, so that you're not sinking in something. I spend a lot of time in South Florida fishing, and every time I go to Miami, I swear everybody likes to sit on the floor [00:38:00] because I call it the Miami [inaudible 00:38:01], everything's about eight inches off the floor. I'm like, "Who designs a sofa like that?"

Mindy Henderson: Wow.

Paul Robertson: But very modern and chic, I guess, would be the term.

Mindy Henderson: I'm sure.

Paul Robertson: Just to highlight a quick other couple of things.

Mindy Henderson: Sure.

Paul Robertson: Dual handrails on all the staircases.

Mindy Henderson: Yes.

Paul Robertson: We've got an elevator, but... And when you put those in, again, ripped them out. Lots of wood blocking. Really secure, just in case. We did a home generator [00:38:30] system, mostly because of the elevator. That was the biggest thing.

Mindy Henderson: Oh, so smart.

Paul Robertson: Power's pretty stable here, but Murphy's law has it that when I need to get out of the house, I need to be able to use the elevator.

Mindy Henderson: Absolutely.

Paul Robertson: And then, the final thing that I think I could tell you that we did, that I think has really been beneficial was we put an integrated smart home system in. And so, what do I mean by that? And so, all of our lighting, all of our security, all of our door locks, all of our TVs, stereo [inaudible 00:39:00], [00:39:00] are all integrated through one electronic system that's controllable by either a handheld remote, your telephone, by an app, or on like a tablet that's mounted to the wall.

The way that that started was... And of course it morphed into a bigger project. You know how building is, it morphed into something bigger.

Mindy Henderson: Oh, yeah.

Paul Robertson: But I reached out to multiple electrical contractors and I said, "I want to have a light system in the house." The reason behind that was that if I was here alone and I was [00:39:30] leaving, I didn't want to take 30 minutes, this is what it would take me to go room by room, to turn everything off. It's called an ELAN system, E-L-A-N. Not trying to plug them, but just what it is.

Mindy Henderson: [inaudible 00:39:44].

Paul Robertson: It integrates everything. I can hit a button and all the doors lock. I can hit a button and the garage doors close, or [inaudible 00:39:50]-

Mindy Henderson: Wow.

Paul Robertson: ... thermostat control. I'm sitting at my desk now, but I can literally sit here and control basically everything in the house. I can shut the lights off. I can lock the doors. [00:40:00] I can turn the music on, TV on. We've got four kids, so you know what that's like. You've got to leave and you're out. You're pulling out of your driveway and you look up and you see that all the lights are left on.

Mindy Henderson: Only seven lights are on. Yep.

Paul Robertson: That smart system, to me, was probably one of the most important things, because I didn't want to have to find myself having to go check all the doors, are they locked? Are the lights switches off? Did the kids leave the TV on with their video games? Or whatever it was. Ironically, I can shut [00:40:30] it all down when I go to bed too, and then the kids password it out. Can't turn it on if they don't walk.

Mindy Henderson: Right.

Paul Robertson: But yeah, we don't do that. We [inaudible 00:40:38] about that. We could choose to shut it all down. But I think that, if you are building a new home, or you are doing a renovation and accessibility, from a mobility standpoint, or disability is a big deal, definitely invest some serious time into some of the technologies that are out there because it makes your life so much easier.

If you're sitting in the chair and you say, "Hey, you know [00:41:00] what, I'm watching TV in the family room." And the kitchen lights are real bright, now I've got to get up, turn them down. If you can just take your phone... It makes you feel a little lazy, but on the flip side, us with this disabilities, if you've got to get up and out of the chair, you've got to move over here and go to this room.

Mindy Henderson: So handy.

Paul Robertson: What seems like is just a regular thing for someone without a disability, just to get up and walk into the next room and turn something off, for us, I always say, it can be like running five miles for them.

Mindy Henderson: Absolutely. Yeah.

Paul Robertson: So technology, I think it's so important. [00:41:30] If you do it during a renovation or you do it during a construction process and you plan it... I spent a lot of time with our technology representative, talking about the disabilities, talking about, how do I get the lights to adjust? An exterior lighting was another thing.

Mindy Henderson: [inaudible 00:41:48].

Paul Robertson: We have full perimeter lighting, down lighting around the house so that... I poured concrete all the way around the house so I can walk around the entire house. My primary residence, that we will eventually move [00:42:00] from to here, I can only go on the driveway. I can't get around the house. It's grass, it's mulch beds.

Mindy Henderson: Sure.

Paul Robertson: And I wanted to walk around my house at the end of the day. But when you do that, I put little soft glow lighting that goes down and it's controlled by the smart system. That way, you don't have to worry about... I could be walking and there's [inaudible 00:42:19] there and I kick it with my foot, I'm probably going to fall.

Mindy Henderson: Right.

Paul Robertson: Where most people, it doesn't even affect them. Or if there's a rock, a pebble, and you step on it. That's what we deal with, living [00:42:30] with muscular dystrophy. So technology, I think, is something that a lot of people don't look into. They think after the fact, after the fact, "How am I going to control this light or this TV?" But we planned it on the front end. Again, it morphed from a lighting and door lock project into a whole home system.

But certainly, I would say, one of the best things we definitely did was investigate and invest in technology to make the house what's a "smart home". But make [00:43:00] it smart because it makes it so much easier for me. So that was a big thing too.

Mindy Henderson: Definitely. I've even heard of smart home technology that will adjust the blinds in your windows and things like that.

Paul Robertson: We actually have those on order right now.

Mindy Henderson: Oh my gosh.

Paul Robertson: That integrates through the system. We got [inaudible 00:43:22], these paper blinds up now. But that's just like turning the lights off. If you have four blinds in a room and you're mobility [00:43:30] challenged, and you've got to go get all of

those closed, that's a lot of work and a lot of effort. So that was important. The other thing we did, we used the pre engineered flooring. Looks like wood, but it's really vinyl. It's real popular right now.

There's a lot of different manufacturers out there. We used the Coretec brand. But for me, that was really important. That's in most of the house. I'd think that it gives you a good, solid surface to walk on. Someone told me not too long ago, that some of the biggest trip hazards for people [00:44:00] in homes were shower curtains, bedspreads, and area rugs, those three things.

Mindy Henderson: Yes.

Paul Robertson: So we did glass doors in the shower. I'm not an area rug fan at all. And yeah, just to make sure that your bedspread's not these big overflowing bedspread that when you get out of bed, your feet get tangled, twisted, or whatever it may be.

Mindy Henderson: Great point.

Paul Robertson: Those are the three things that someone told me a while ago were the three most common home... If you want to call it trip or slip issues out there. So that and [00:44:30] a carpet. We did do carpet in the bedroom and a couple of rooms, and all that's low pile Berber, thin pad below it. If I get in a real plush carpet, I feel like I'm walking on sand. If I walk in sand, I guarantee you I'm going to fall.

Mindy Henderson: Yeah. Well, and same thing with a wheelchair. Wheels are so hard on carpet. A month in and your carpet looks like a disaster because you've worn it down and gotten it dirty. So in my house, we've got mostly tile, probably in 90% of the house.

Paul Robertson: Right. Right.

Mindy Henderson: Yeah. [00:45:00] Well, this is fascinating. It sounds like you've been incredibly thorough. Like I said, an incredibly creative visual. I can't thank you enough for spending your-

Paul Robertson: Yeah. No, that's great.

Mindy Henderson: ... time and your expertise with us.

Paul Robertson: It's great. No, and I appreciate it. If I could put a plug in for our fishing team, if anybody's out there. They can follow us on social media. We're constantly increasing awareness for muscular dystrophy and it would be great. It's Fishing For MD. Or you can just Google fishing and muscular [00:45:30] dystrophy and we come up all over the place. There's YouTube videos on their podcast, or our hashtag is FFMD.

If anybody's out there and they can follow us on social, we always appreciate it. It helps us continue our quest to increase awareness in what we feel is a really big demographic area, the boating and fishing community.

Mindy Henderson: Perfect. We'll put all of those links and things in the show notes as well, so that-

Paul Robertson: Awesome.

Mindy Henderson: ... people can be sure to find them. Well, thank you again, Paul. I appreciate it. And-

Paul Robertson: Yeah. [00:46:00] But thanks for having me, definitely.

Mindy Henderson: Absolutely. Absolutely. It's been a pleasure. Thanks so much. Thank you for listening. For more information about the guests you heard from today, go check them out at mda.org/podcast. To learn more about the Muscular Dystrophy Association, the services we provide, how you can get involved, and to subscribe to Quest magazine or to Quest Newsletter, please go to [00:46:30] mda.org/quest.

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