

Episode 29: Expert Accessible Travel Tips for Your Next Vacation (Travel with Sylvia & Cory) April 27, 2023

(Music playing)

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, 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.

Well, welcome everyone. I am thrilled to have two award-winning travel writers with us today to share their tips and tricks for accessible travel. Starting with ladies first, Sylvia Longmire is a service-disabled Air Force veteran and former Ms. Wheelchair USA 2016. She's the author of four accessible travel books, and the creator of Spin the Globe accessible travel blog. And I would be remiss if I didn't mention that she's also a director, producer, voice actor, and staunch advocate for accessibility and disability representation.

And not to be outdone, we have Cory Lee, who runs his travel blog called, curbfreewithcorylee.com. He has also won multiple awards and is written for publications such as Condé Nast Traveller, National Geographic, and Lonely Planet. Cory lives with spinal muscular atrophy and has traveled across all seven continents in his power wheelchair, which is phenomenal.

Thank you both so much for being here. Travel is always such a popular topic when we talk about it or write about it here at Quest Media. And I have a longer

list of questions than I think we can probably get to, so I'm going to dive right in. But thank you both for being here.

Cory Lee: Yeah, thanks so much for having me.

Sylvia Longmire: Thanks for having us, Mindy.

Mindy Henderson: Absolutely. So, I don't know who wants to start first, but I'm curious how you

each got into travel writing?

Cory Lee: Okay, I'll start first. So, I started Curb Free with Cory Lee, my blog, in December

of 2013. And I started it after... I was actually researching for a trip to Australia and got online and pretty quickly noticed that there was very little accessible travel information on the internet. And so, I wanted to create a resource where other wheelchair users could go to and hopefully find out what's accessible, what can they do once they get there, and why should they travel as a

wheelchair user and how is that even possible.

So, I launched Curb Free with Cory Lee just to share my experiences. I had not been to very many places at that time, but I thought if I can write about the places I've already been to, and then as I travel, I'll just keep publishing content, hopefully, people will see it and resonate with it and find it helpful. And luckily, they did. And in the past 10 years, it's been a wild ride. I've been to over 40 countries in the past 10 years and all seven continents, and lots more fun travels

plan coming up. So, it's been a fun journey.

Mindy Henderson: Amazing. Sylvia, how about you?

Sylvia Longmire: Yeah, Cory actually paved the way for me, so I'm eternally grateful to him for

that. I started traveling solo as a wheelchair user in 2015 after my divorce, and I had traveled a little bit for work with a walker, but I had never traveled by myself with my... I have multiple sclerosis, 18 years. I've been using a wheelchair full-time for about 8 years. And just like Cory said, there really wasn't that much information out there. And one of the first places I went in 2016 internationally was Iceland, and I found Cory's blog post about that, and some other

information and places Cory had been. And I was like, "Well, all right, there's some information on here, let's give it a shot." And that kind of started that

journey.

And after the first year, I had gone to Dubai on my own. I went on a cruise, my first cruise as a wheelchair user, as a scooter user. I went to Iceland by myself, and I went to Australia by myself, and I said, "You know, I'm a professional writer." I had been writing for about a dozen years as a subject matter on border security and Mexico's drug war, and I had a couple books out on that already. I'm like, "Look, I'm a professional writer. Why am I not writing about travel?" And I kind of use Cory as a template, as a guide and started my own

blog, Spin the Globe, and that was in late 2016. So yeah, we've just been helping each other out and I've been following in his footsteps ever since.

Mindy Henderson:

So great. So great. And selfishly, I do have to tell you guys, I am going to be traveling by a plane for the first time in 14 years, and I think that probably all of us know why that might be. Air travel is not a thing that has been perfected for wheelchair users just yet. And so that is yet another reason why I'm so excited to talk to you both today.

And we'll get to air travel and more in just a second but traveling with a physical disability adds a whole new level of planning to travel. Do you mind sharing with us just a little bit more, so that we can kind of paint a picture for people who may be listening about how your diagnosis specifically impacts your mobility and what sort of mobility devices you travel with?

Cory Lee:

So, I have spinal muscular atrophy type 2. I have used the powered wheelchair since the age of four. And so, with SMA, I'm sure a lot of people watching already know, but I'll kind of go over it anyway. It is a genetic disorder and it's also degenerative. So, I don't have the same abilities today that I'll have five years into the future. And so, I do get weaker over time. So now I do require a care attendant to travel with me on all trips, and to be able to do things like transferring me into the bed or into the shower, getting dressed in the mornings, different things like that.

So, I think for wheelchair users, if you do need that level of care, that is an added cost that you have to think about. And it's twice as expensive as if you could just travel solo unfortunately. Which I know Sylvia is able to do, which is amazing. But for me, it's like I always have to come to think about, "Well, it's not only one flight for \$2,000, I got to book two flights and it's \$4,000." It's so much to think about and worry about, and a little unfair I think in many ways. But there are some airlines... Air Canada, I know that they, I think, will let care attendants fly for free in Canada, but I think they're the only airline that I know of that's doing that.

Mindy Henderson:

Yeah. Wow. Well, hopefully other airlines will follow suit. That's tip number one that I was not aware of. So that's kind of amazing. So, Sylvia, what about you?

Sylvia Longmire:

So again, I have MS and I have a little more physical ability than Cory does, so that allows me to travel by myself. But I still have my own challenges. I have a small power wheelchair that I travel with, and it comes apart in three pieces, which is necessary for me because not every place that I go has accessible transportation. So, I'm physically able to plant my feet and pivot. I can't walk or lift my legs on my own, but if I have to pivot into a taxi or an Uber, as long as it's a sedan, it's doable. It's dangerous, I don't like doing it, but it's possible. So, I have a little more leeway with that regard.

However, like SMA, MS is also progressive, so I don't know. And it's unpredictable, so I don't know if I'll be getting out of bed in 5 years, 10 years, I'm not sure. And it has progressed, and I'm still able to travel alone, but it's getting a little harder. Leg spasms flying on planes for eight or nine hours. We just got back from Portugal a couple of months ago, and that was kind of brutal just being on the plane for so long. So, it just affects me in different ways.

I do travel mostly by myself. I've recently started traveling with a companion simply because she's a... Well, not simply because she's awesome to travel with, but she's also a professional photographer. And some of the destinations I'm working with, I like having her along for that for content and stuff. And I'm glad I had her with me in Portugal. I had a robust accident out there and got pretty injured, and I definitely needed her physical help, which I've never really needed that on a trip because you just never know when you're going to get hurt or have an accident or something like that.

So, moving forward, like Cory says, yeah, that it's an extra expense, and if they can't afford to go, then you're paying for them. I cruise by myself all the time, and I have to pay twice because there's a solo supplement, so you're not paying for the bed, you're paying for the entire cabin. So, if I see a price on a cruise and it's a \$1000 for a week, then it's like, "No, that's \$2,000." I definitely find that unfair that I got to pay double when I go on cruises, but that's one of the downsides of solo travel. But yeah, that's kind of how my MS and my chair and stuff, how I deal with that.

Mindy Henderson:

Interesting. I want to probe just a little bit more at that chair, because I've had other travel conversations and this was a big question that a lot of people had, and it's interesting. I'm intrigued by this chair that you have that can come apart. Is it a manual chair or an electric chair?

Sylvia Longmire:

Oh, no, no, no. It's a power chair.

Mindy Henderson:

It's a power chair?

Sylvia Longmire:

It's a power chair. Yeah, it's 115 pounds. The company's called Whill, W-H-I-L-L, and the model I travel with is a C2. Five miles an hour, it separates into three pieces, and it'll send fit in the trunk of a sedan. The main attractions are the omni wheels in the front. They're almost a foot wide, and then they rotate side to side on individual ball bearings, so the wheels don't pivot. They're solid. So, it's got a very, very small turn radius.

And then Whill also has another chair. It's called the Model F, that's newer. That one's only 59 pounds with the battery and it folds. And there are a lot of folding chairs that are out there in the market, I think this one looks the best. It's nice and sleek. But it's for folks who have just a tiny little bit of mobility because lateral transfers aren't possible. But just the fact that it's compact, it's lightweight, it folds, and especially for cruises, because the cabin space on

cruises is very limited, and some people can't get an accessible cabin and don't really need one. So, a folding chair is a good option for folks that just need it for longer distances.

Mindy Henderson:

So is that kind of chair... Because I do want to talk about air travel now. Is that kind of chair something that you can pull apart and stow in the closet in cabin with you? Or it does still have to go under with the baggage?

Sylvia Longmire:

Yeah, I mean, it's a full power chair. I never have to take it apart to fly with it. I think I've only to do it once where they had to take the seat off, and that was on a KLM flight out of Amsterdam. And just the cargo hold door was tiny. Because the seat back folds down, my chair is very small. But no, it's still a power chair, so it needs to go in the hold just like every other power chair, I guess you could say.

Mindy Henderson:

Okay. So let me go ahead and ask because you do both use chairs. So how do you fly... And we hear the horror stories about damage that gets done to power chairs when people fly, how do you fly and manage to mitigate? Have you found any effective ways for working with the airlines or things you can do ahead of time to try to mitigate damage to your chairs?

Sylvia Longmire:

Lots of crossed fingers.

Cory and I are in very different situations when it comes to that, and his answer will be a lot more useful than mine. One of the reasons that I like my chair is because it has almost no protruding part. The only thing that protrudes a little bit is the joystick, and it's kind of flat, and we're actually coming up with a prototype cover to snap on to cover that. But I have no protruding wires, nothing that'll snap off. I get some cosmetic damage on the arm covers, but it's a sturdy chair and one of the reasons I like it is just it's not prone to damage. But Cory's chair is a completely different beast, and I'll let him talk about that.

Mindy Henderson:

Sure.

Cory Lee:

Yeah, my wheelchair weighs almost four times as much as Sylvia's. So, it's 400 pounds. It's a Quickie Q700 M model, so it's pretty big. So, flying with it is a hassle for sure, but I always just make sure to call the airline in advance, let them know the dimensions of my wheelchair, the width, the height, the length, how much it weighs, everything. And also, that it's a dry cell battery or a gel cell, so they're not trying to get me to take the battery out before the flight and that it can be able to fly and all that. So definitely let them know that in advance of your flight. And then once I'm actually at the airport right before I get on the plane, when I'm at the gate or the plane door and I have to give my chair over again into the aisle chair, we always tape any parts of it that can come off, take them off, put them in a carry-on bag and take them in the plane with you.

So, I always take off my headrest. I have knee pads that go on, so I always take the knee pads off. We always take my cushion off, and I sit on the cushion in the plane just to be more comfortable throughout the flight on my own, like Roho cushion. And then once all the parts are removed... We always take bubble wrap with us, and we bubble wrap the joystick and the armrests. And so, the joystick for me is usually the number one thing that gets damaged whenever I'm flying. It's been damaged a couple of times so badly that I couldn't even drive myself out of the airport when we arrived back at home in Atlanta. And so ever since then we've started just bubble wrapping it, and then we also take some tape with us, like duct tape, and we duct tape the bubble wrap on. So, we do take all of that with us. The airline does not provide the bubble wrap or the duct tape, so definitely take that with you, and then just be sure to let them tape and bubble wrap that joystick really, really well.

And that system has worked pretty well for me. The only kind of damage I've had since we've started doing that is if the door is too small on the plane to load the wheelchair upright, they will need to lay it on its side, or I'll lay the backrest back really far to make it not as high. And so, when they do lay it on its side sometimes, if it's a smaller plane, then it will damage that left armrest up, or it may get a few scratches here and there. But it's never been anything where I couldn't drive out of the airport. So, I think the number one thing to keep in mind is just letting the airline know in advance exactly the dimensions, the weight of the chair, what they can best do to assist you, and then taking the bubble wrap and the duct tape to be able to securely get that joystick covered and in good shape.

And then like Sylvia said, you just got to cross your fingers and hope for the best.

Mindy Henderson:

Yeah, it's true. I think faith in the process is a big part of it. So let me ask you about the batteries. Because 14 years ago when I did still fly, I know that even if I told them that I had a dry cell battery, they would still take the battery out. Do you come up against that?

Cory Lee:

Yeah, this happened to me a few years ago I think... Well, more than a few years I guess, like 2016 or 2017. I was flying to Israel and got into Tel Aviv in the airport. It was like middle of the night. We were so tired. We just flew all day and night to get there, and they brought my wheelchair up to me and the battery was sitting in the seat. And so, they ripped it out and it was just sitting in the seat. It took us three hours to figure out how to get the battery back in.

Mindy Henderson: Yep. They're not easy to get back in.

Cory Lee: No, it was so difficult, but we finally got it and then it all worked out. But yeah, it

was rough.

Mindy Henderson: Okay.

Sylvia Longmire: I remember that.

Mindy Henderson: I've heard of people putting laminated signs over the batteries saying, "Dry cell,

do not remove."

Cory Lee: I do actually... Delta, which I usually fly with like 99% of the time, they now offer

on their website... I don't know where it's out in their website, but they offer a link where there's a form that you can fill out with any instructions that you want the ground crew to know about like, hold your wheelchair properly, and any extra stuff you want them to know too. So, I always take that, it is laminated, and I put that on my wheelchair. And then if I'm traveling somewhere internationally that maybe doesn't speak English, I also print out the sign in their native language. I just use Google Translate for that. And so,

putting that in their native language also seems to help.

Mindy Henderson: Nice. I want to move on to lots of other topics, but before I do that, what about

transfers? I think we've mentioned the infamous aisle seats that you have to transfer into and that sort of thing. Any tips or tricks for making those transfers

go smoothly?

Cory Lee: I can talk about what I use for just a second. It'll be really quick. It's called the

ableSling. It's made in the UK. It's just a sling that I sit under, and it has handles on it. So, the airline staff is able to easily lift me up and over into the aisle chair and then into the plane seat. So that has worked phenomenally well for me. There are also some companies in the US. I know there's the Perfect Lift, which is made here in the US by a mom of someone with Duchenne muscular

dystrophy. There's the Adapts Travel Sling. There are quite a few options, but

those transfer slings tend to work really, really well for me.

Mindy Henderson: Great. Cynthia, anything for you to add? It sounds like you may have a little

more mobility in this area than some of the rest of us.

Sylvia Longmire: I do. It was easier for me. I used to be able to self-transfer between my chair

and the aisle chair, and then the aisle chair and my plane seat. But now that my spasms are getting worse in my legs, it's just so much easier and less... It's faster if I just say, "Just give me a full lift," and they do a full lift. Knock on wood, I haven't been dropped yet, but there have been some places, especially in other countries, and it just depends on the airport staff that are moving you where they've come close to knocking my knees or my feet into things, or my feet are slipping off and I'm trying to tell them to stop to put my feet back on the plate.

And I've had to say, "No, no, no," like eight times, then they just...

So, communication, I used to worry too much about... "Make sure you're nice and you're polite." I'm 48 years old and I've been all over the world, and I just don't have the patience anymore to be polite when it comes to my safety. I have no trouble communicating as forcefully as I need to because it's my body and I'm the one who needs to advocate for making sure that I don't end up in a

hospital again. So yeah, communication is key about what you need and what you don't want them to do.

Mindy Henderson:

Okay, perfect. Great. So, let's move on to transportation. So, transportation, let's start with things like from the airport to your hotel or whatever. Actually, for one of my trips coming up, I've been asking hotels if they have accessible shuttles, and I don't think I have found any that do. So, what are your tips for getting transportation where you need to go once you get to where you're going?

Sylvia Longmire:

It totally depends on the place. I mean, completely depends. I have found some hotels that have accessible shuttles. I fly... I used to anyway, when I was going to Asia more, I would fly to LAX a lot because I can't do that trip to Asia in one shot. So, I'll fly to LAX, or I'll fly to San Francisco, I'll spend the night there, and then the next day I'll head on.

So, I always stay at the same hotel when I go to LA because I know they have an accessible shuttle. So that is one thing that I do. If I'm flying overseas, if I'm working with an accessible tour company, then they'll have a van ready for me to take me from the airport to the hotel. Other places, I've taken public transportation. Like let's say Portland, Maine, they have accessible buses. They don't have accessible taxis, but they have a bus that runs a direct route from the Portland airport to City Center. So, I'll do that. And in other cities, Seattle, and DC. Especially in DC, the metro will go direct... has a metro stop at the airport, so that's useful. And then in other places, like in London, Heathrow where all the black cabs are accessible, getting an accessible taxi is super easy. In Toronto, they have the Uber WAV, the wheelchair accessible Ubers are really easy to come by.

And then there's my hometown of Orlando, which is awful. I mean, it's Disney, but there's only one company that runs all the accessible taxis, and they're few and far between. And it's terrible. The availability of the accessible taxis here is awful, which really boggles the mind because we've got Universal and Disney or whatever. But I live here, so I've never really had to work it. But a mutual friend of ours that Cory and I know, he struggled when he lived here getting a wheelchair taxi, especially at late hours out of Orlando Airport. So yeah, it really just depends on the destination.

Mindy Henderson:

Okay. Cory, what are your thoughts?

Cory Lee:

Yeah, I mean as Sylvia said, I think it totally depends on the destination. But one thing I've started doing in the US in the last few years is using just accessible rental vans. And one company that I use a lot is MobilityWorks. And so, they're available in pretty much most major US cities. You can usually find a MobilityWorks. And so, I use them just for accessible van rentals. They're able to remove the passenger seat, they have the tie-downs and a ramp, so I'm able to get in the van easily. So that's worked really well for me in the US.

And then internationally if they don't have really good accessible public transportation... Some cities do, but they're kind of far and few between. If they don't, then I will use an accessible tour company. And so, by arranging my trip through an accessible tour company, they already have the accessible transportation. They have figured all of that out already, and I'm able to just go, show up at the airport, and then they're there with a sign with my name on it so I can leave that airport and then they have all the transportation that I need. So, it's worked really, really well for me. So, I don't think that I've actually taken an international trip in probably seven years where I did not arrange that trip through an accessible tour company, just because they make it so much easier.

Mindy Henderson:

That's amazing. So, do you have any accessible tour companies that operate in across the country that you can recommend? Or does it again just really... Do you have to do the research depending on where you're going?

Cory Lee:

Yeah, you really just have to do it depending on where you're going. Because internationally, every destination has a different company. So, in Morocco, there's like Morocco Accessible Travel Consultants, and they have an accessible van. But then in Helsinki, Finland, it's like there's a totally different company. So you really just have to do that research ahead of time and just scout mine and Sylvia's blog to find the details.

Mindy Henderson:

Yeah. Okay. And then last question on this, but how do you check out reliability of those companies? You don't want to be left stranded at the airport and those sorts of things.

Cory Lee:

Yeah, so I depend on... The opinions of what other wheelchair users is invaluable to me. So, I use Facebook groups, Accessible Travel Club is a great one. It has over, I think, 15,000 members.

Sylvia Longmire:

Yeah, they're at about 15,000 now.

Cory Lee:

So, if there's anywhere that I'm thinking about going that I haven't already been to, I can just pop a question in that group. And usually somebody in the group has been there, done that, so they're able to provide some input.

Mindy Henderson:

Love it. Love it. What about trains? First of all, have either of you traveled on something like Amtrak, for example, here in the States?

Sylvia Longmire:

I actually did a promotional campaign for Amtrak about three years ago on the auto train. Because I live in Sanford, Florida, which is one of the end points, and it goes from Sanford to Lorton in Virginia, just south of Washington DC. So, it was an overnight, and I was able to take my van. I did not sleep. I had a sleeper cabin, but oh my God. After you go on a European train that's smooth like butter and goes 160 miles an hour, and then you're on Amtrak where it's maybe 55 miles an hour and you feel like you're going to get thrown out of your bed at any given point of time. It was not my idea of a good time.

The little cabin... I was in my scooter at the time, I didn't have my Whill, and it was really hard for me to turn around. I had to time the transfers to the toilet when we were going slow through a town. And like, "Okay, I don't care if I have to pee or not. Now is when I'm going to transfer because the trains are not moving that much." But trying to sleep was next to impossible. But it was nice that I could bring my van with me, but I'm glad I did it once, and I don't need to do it again.

I have done shorter routes, and those were a little nicer. But there was plenty of room, especially on Amtrak. Plenty of room, the accessibility was good, the bathrooms were big, and the accessibility was good. And I've done trains in almost every country that I've been to, in Europe. And I've done metros but not like train trains in Asia. But yeah, I've done trains all over Europe and I love them. They're fast, they're clean, the accessibility is good. They bring you anything you want as food. You don't even have to go to the cart. I'm always worried that they're going to leave me on the train, but there's little buttons and stuff in the wheelchair compartments, and they're always checking on you and stuff. So, I've had really, really good experiences with trains in Europe.

Mindy Henderson:

Amazing. Cory?

Cory Lee:

Yeah, I mean, pretty much exactly what Sylvia said. I've only done Amtrak here in the US once, and it was just a four-hour trip from DC to New York and back. So, it was okay. I mean, I wasn't a huge fan. But I wasn't there overnight, so I don't really know what that's like. But in Europe, the train system is phenomenal. I think they're so far ahead of the game of the game compared to us here in the US. And European trains are phenomenally accessible and the teams there that help you get on the train and maneuver into your seating area, super friendly and nice. So, I'm a big fan of train travel in Europe, but not so much in the US. But it is definitely possible. I mean, Amtrak is accessible if you want to use it. So that's definitely an option.

Mindy Henderson:

Okay. I've always wondered about it as an alternative to flying because you can stay in your chair and all of that. I personally need to use a Hoyer lift, which I want to talk to you guys about in a second. I don't know if either one of you use one of those or if other methods of transfer work for you, but I don't know that a Hoyer lift... Or maybe it would. Would a Hoyer lift work on an Amtrak or a European train if you were going to do an overnight train?

Cory Lee:

I use a Hoyer lift, but I have never done an overnight train, so I am not 100% sure.

Sylvia Longmire:

There's no way. I mean, I could barely fit myself and my scooter inside that little cabin. And plus, the bed in that compartment, it was like a bunk bed. So, the lower bed was like two... You'd sit in chairs, regular seats, and then the seats go flat and then kind of link up and that becomes the bed on the bottom bunk. And then the only other overnight train that I did was in Norway, and it was an accessible compartment, but it was a tight squeeze. And again, it was like a bunk

bed situation. I'm able to, like I said, pivot and self-transfer onto the bed. Plus, it wasn't a very long ride, I just slept in my clothes. But there's no way in a million years you'd be able to get a Hoyer lift or anything like that. You can barely get yourself in there.

Mindy Henderson:

Gotcha. Okay. So, let's talk about hotels for just a second. Because I kid you not, I'm going to New York in June, and I spent two hours on the phone earlier this week talking to probably 20 hotels, looking for a hotel room that had clearance under the bed so that I could roll a Hoyer lift under to get into the bed. And I couldn't find anything. I'm still working on it, but nothing. And I've had similar... I mean, Houston, San Antonio, other places in Texas that are closer to me, I have dismal luck trying to find that clearance under the bed. So, I'm wondering, first of all, if you have had the same experience, and if so, have you found any workarounds at all?

Cory Lee:

I actually dealt with this week because this weekend I'm going to see Taylor Swift in Atlanta. And so, I booked a hotel right beside the stadium the day that the concert was announced because I knew the prices would go up after that. So, I booked it immediately and I called the hotel to make sure that a Hoyer lift can go under the beds, it's an accessible room with a roll-in and two clean beds. And the hotel told me that zero rooms in the property have clearance, so they're all on block frame.

And so, I suggested, "What about like a rollaway bed?" Because that's something that I use a lot, which is not the ideal scenario, but for this case, that hotel is really the only one within walking distance of the stadium where the concert is. And so, they changed me from a room with two queen beds to a room with one king bed, and then they're going to put a rollaway bed in there. So, the rollaway bed does have clearance under it, they say, so that should work. And I've done that many times in the past where if you've got to have the Hoyer lift, then the rollaway may be your best option. Or a pullout couch as well, because those usually have a good bit of clearance underneath also.

Mindy Henderson:

Okay. Have you ever had a rollaway bed where you showed up and it didn't have the clearance underneath?

Cory Lee:

No. So, everyone I've ever used has always had clearance. So, they've been really good in my past experiences. I ask them... I mean, we were on the phone for over an hour with this hotel, making sure, and they assured me that it will work. But also request photos of the accessible room just to be double sure that it really, really, really will work for you, and the hotel managers and housekeeping is usually happy to take a quick picture and text it over to you or email it.

Mindy Henderson:

How did I not think of a rollaway bed? That's brilliant.

Cory Lee: Yeah, they're not the most comfortable compared to the normal beds we know,

but they're not bad. They work. If you're only there for a couple of nights, it's

totally fine.

Mindy Henderson: Yeah. And I never sleep well in hotels anyway.

Cory Lee: Right.

Mindy Henderson: Yeah. What about Airbnbs? Have you stayed in those, and what kind of success

or not have you had?

Sylvia Longmire: No. And I was a travel agent for three years, so I'm familiar with the difference

between the hotels and the Airbnb as far as the structure and the model and all this and this. And even a travel agent will tell you, "Don't stay in an Airbnb," for many, many reasons. Not even touching the accessibility, is that based on the agreement, the host can change their mind and cancel on you. I've had so many friends that have gone across the globe and showed up in Paris at 1:00 in the morning and gone to check-in at their Airbnb and the host just canceled and said, "Hey, sorry, we can't do it." And they're left without a place to stay.

Mindy Henderson: A nightmare.

Sylvia Longmire: The biggest downside with Airbnb, they do not have to abide by ADA guidelines.

So, the definition of accessible to the property owner may not be your definition of accessible. But the biggest thing is that if they have some sort of ADA violation, you can't hold them accountable for it. So, you can't file an ADA lawsuit. They've gotten better as far as pictures and descriptions and being a little more detailed on what they offer, and they do work for a lot of people. Again, I usually travel by myself. Even if I travel with somebody, they can't pick me up and put me in bed, I still have to be able to self-transfer. I need a bathroom that has a bench, or at least a chair that's already in there. I don't like

using a loose chair because it's just not very stable.

So, it's kind of hit or miss and you don't really know what the setup is going to be because again, some of these adaptations are put in after the initial construction. They're not necessarily purpose-built Airbnbs with the intent to make it accessible unless you have somebody who's a senior or somebody who already has a mobility challenge, and they were already wheelchair accessible for the homeowner or the person who lived there. But that's kind of a unicorn to find.

And another problem for me when I travel especially overseas, but even domestically, Airbnbs are houses. So, they're usually in residential areas, which means that they're usually not close to transportation. Now if you're driving, that's one thing, but if you're flying somewhere, getting to and from the Airbnb and wherever you want to see, especially if you're there as a tourist, can be

very, very challenging. So that combination of things and... Nope, totally not interested.

Mindy Henderson: Okay. Anything else to add, Cory?

Cory Lee: Yeah, Airbnb does have an accessibility section now, so you can browse

accessible properties around the world, and the filters are pretty good for the most part. You can sort for roll-in showers, for doorway widths, all kinds of things like that, which is helpful. But for the same reasons as Sylvia said, I have never booked an Airbnb because I'm so afraid that I'll show up and then... I'll

arrive in London and then it'll say, "Oh, we actually..."

So yeah, I'm not probably ever going to book an Airbnb for that reason alone. But if you want to go for it, I do know people that have done it, and they love it. And then I know other people that have showed up to their destination and they were on the street, had nowhere to go. So, it just depends on if you want

to take that risk or not.

Mindy Henderson: Okay. Let's talk actually about durable medical equipment. Because we've

talked about things like Hoyer lifts, I know that maybe shower chairs are another piece of equipment that people... Those are things you really can't take on an airplane. I take my Hoyer lift with me if I'm going someplace within driving distance. But Cory, how do you handle renting of durable medical equipment when you're going somewhere? And have you hit any landmines that we should

be aware of, or any tips in that area?

Cory Lee: Yeah, so if you're going on a cruise, there is a company called Special Needs at

Sea, and they can arrange things like Hoyer lifts or even hospital beds I think, and all kinds of durable medical equipment. And they will have it in your cruise stateroom before you even get there. So, it's like ready to go, you're all good. So

Special Needs at Sea is cruising.

Sylvia Longmire: Full disclosure. I work for Scootaround and Scootaround does the same thing.

Mindy Henderson: Oh my gosh.

Sylvia Longmire: Yeah, they also do it at land-

Mindy Henderson: I've been schlepping my Hoyer lift to my cruises.

Sylvia Longmire: Yeah, and then you don't have to do that. Plus, Scootaround does land based

steps. If you want to go to Vegas, New York. Orlando or anything like that,

they'll do the same thing to your hotel room, your resort, et cetera.

Mindy Henderson: Brilliant.

Sylvia Longmire: A couple companies that do that.

Cory Lee:

And then internationally, I would say I'm just working with the local tour company. So, like I was talking about earlier, if I'm traveling internationally, I'm going to work with the local company that specializes inaccessible tours, and they're usually able to arrange things like getting my Hoyer lifts or portable ramps or any kind of special bedding or whatever you need. So just reaching out to them and asking is a good place to start internationally.

Mindy Henderson:

Amazing. Okay. Let's talk about cruises for just a second. Because I live in Austin, Texas, which is a four-hour drive to Galveston, which you can just drive down and hop on a cruise ship. And I personally have found cruising to be one of the most accessible ways to travel. I don't know if you guys would agree with that. You've done a lot more traveling than me and explored a lot more options, but I love cruises. Tell me your experiences and what sort of tips you have for cruising.

Cory Lee:

I'll let Sylvia go because she's like the queen of cruising.

Sylvia Longmire:

Well, we've both had some really awesome experiences. As a wheelchair user, I think I've done around 30 cruises. And before Covid, I was doing about 10 to 12 a year. I did 7 in just the last three months of last year alone. But yeah, it's tough because of that solo supplement, but I love it. The number one benefit I think to going on a cruise as a wheelchair user is that you get to go to places... Granted it's only for a day, only for several hours. But oftentimes, these are places that you would not be able to travel to by air and stay in a hotel and enjoy for a longer period of time.

Croatia is one of those places for instance. I went on a cruise a few years ago from Venice to Rome and it stopped in Rijeka and Split and Dubrovnik. And I had been wanting to go to Dubrovnik forever because I'm a Game of Thrones fan, and the weather was actually garbage that day, so I didn't see much of it. But at least I saw some of it, and Split was incredible. So, if I had flown into Dubrovnik and wanted to stay there and explore it for a week, it would've been very challenging for finding the hotel room, and especially for transportation, and so many of the things in Croatia that are not accessible, at least in the older parts.

So that I love, in the Caribbean, it's the same thing. There's some places that are more accessible than others in the Caribbean, but you just get to see a lot of places in one particular trip and you can find more and more accessible shore excursions now than you have before. There's a long way to go, but the cruise lines are getting better. There are other tour agencies that provide accessible shore excursions as well. So just the opportunity to see places that you might not be able to travel too otherwise.

And the ships now, especially the newer ships, the accessibility is phenomenal. It's great. Automatic opening doors and lower beds and hand free, touch free controls, accessible seating in the theaters and everything, lifts at the pools... It's just awesome. I love it. I can just go on a cruise every week for the rest of my life, and I'd be totally happy.

Mindy Henderson: Yes, please.

Sylvia Longmire: Yeah. So those are some of the benefits, I think. And yeah, I've been on every

major cruise line except for Cunard. And there are some that are smaller, that are luxury cruises that it's not... The ship's accessibility are okay. They're very, very expensive, but the places that they go, they usually tend to go to smaller ports that the big cruise ships can't get to. So, I don't go on those because, either I can't get off the ship, or if I do get off the ship, I can't get around. So, I would love to go on Azamara or Oceania or Seabourn or something like that, but it's not really feasible. But Norwegian and Royal and Celebrity and Virgin and all

those major cruise lines, the accessibility tends to be quite good.

Mindy Henderson: Okay. So, this is killing me. We have five or seven minutes left and then I do

want to open it up to audience questions just a little bit. I want to ask about tendering and I want to ask about excursions a little bit more, but before I get into that, Cory, is there anything else just in general about cruises you want to

add?

Cory Lee: Yeah. I mean, I think cruising is by far the most accessible way to travel.

Everything you need is right there within the cruise ship. It's like it's on city. So, you can go to dinner, you can go gambling, you can go see a Broadway show, you can go to the pool, do whatever you want, and it's all right there in one location, which is phenomenal. And I've been able to see some really cool destinations also from cruising. One company that I really love in the Caribbean for getting accessible excursions in ports of call is Sage traveling. Or they're

Accessible... What is it, Sylvia? Like Accessible, Caribbean-

Mindy Henderson: Accessible Travel Solutions. But I think they kind of did away with that and now

they just brought it all under Sage Travel.

Cory Lee: Okay. So, Sage Traveling, and they do European ports of call and also the

Caribbean. And then in Europe, I also really love Disabled Accessible Travel. They're great for arranging shore excursions within European ports of call. Or just like land-based tours also. If you're not doing a cruise and you just want to go to Spain for a week or two, then you can hit them up. Also, they'll arrange hotels that are accessible, transportation tours, everything. So Disabled

Accessible Travel is amazing as well.

Mindy Henderson: So, let's talk about excursions though for just a second. And it sounds like you

have a company or two that you've had good experiences with. I don't know if this is true, but I've always been a little hesitant to book outside of the cruise line's excursions because... And I don't want to panic people, but I've heard that if you went with another company outside the cruise line and something

happens, and the excursion is late getting back-

Sylvia Longmire: The ship will leave you.

Mindy Henderson: Yeah. And I've heard that if you go with the cruise line's excursions, they are

bound and required to stay until everyone is back on board. So, what are your

thoughts on that?

Sylvia Longmire: Yeah, that is true. And I thank God I've never had an issue with that. Knock on

wood. And there are pros and cons. You go with the cruise line's shore excursion, you're going to pay a lot less money, which is really nice because...

Again, I travel alone, so it's nice to have that kind of private tour. But

independent shore excursions that are accessible are, I would say, 9 times out of

10 just so expensive. So expensive.

Mindy Henderson: Yeah.

Sylvia Longmire: So, unless you're dividing up that cost among several people, it is going to hit

you in the pocketbook. Mind you, these are small companies, they're local. Buying the van and maintaining the van is very expensive, so I totally get it. But if you're going with the cruise line shore excursion, many times you're going to be on a big coach bus or a big shuttle with a lot of people. And I always feel bad slowing people down sometimes. I mean, my chair goes fast, but sometimes I have to take an alternate route, especially if it's in a place that's not super

accessible. But it is nice to have the tour guide.

It's pros and cons really when it comes to that. But if you book through the cruise line, the ship won't leave. If you book outside and you run late, yes, the

ship will leave you.

Cory Lee: Yeah. Okay. I have only actually done shore excursions on one cruise line,

Holland America, when I did their Alaska cruise. So, all of the shore excursions in Alaska were arranged by Holland America. And they were great, they were fantastic. But for every other cruise that I've done all over the Caribbean and Europe, it's just been through individual tour companies within those destinations outside of the cruise line, and they've never been late. So, I've gotten lucky with that, I guess. But it's worked out really well, and I've had some amazing experiences, those shore excursions by outside companies. So, I don't think there's necessarily anything to worry about. I mean, just plan. If your

cruise is leaving at five o'clock, plan to be back at three just to be safe.

Mindy Henderson: Okay. Okay. Good tip. I was going to ask you about tendering, but in the interest

of time, I'm just going to tell people in my own experience.

Tendering is if the cruise ship can't get quite all the way into the port, there may be a smaller boat that you have to get off of the cruise ship and take to the land, to the port where you're going. Which is not usually something that's terribly wheelchair accessible. Feel free to correct me if you've had other experiences. What I would say is if you book a cruise, just talk to your travel agent or the cruise company, the cruise line, and ask them if you're going to have to tender at any of the ports of call. And maybe just factor that into your decision making

about where you decide to go. I've gone on cruises where you stop at three or four different places, and maybe one of them you have to tender. And it's hard to get around, particularly in the Caribbean. But staying on the ship for a day and laying by the pool or whatever is not a hardship. So, if I can go to three out of four of the places, that's not terribly bad.

So, I do want to ask you about packing tips. Is there anything thing that you found really useful in terms of packing, whether it's product you use or just how you do it. Cory, I know you travel with a caregiver, so you've got your luggage and the caregiver has their luggage. So, figuring out how you're going to get everything on the airplane or on the cruise ship or whatever can be a challenge. So how do you guys' approach packing?

Cory Lee: So, I am probably the worst person to ask about this because I'm a chronic over-

packer, as Sylvia knows.

Sylvia Longmire: Yeah. He and his mom take the whole house.

Cory Lee: Me and Sylvia have cruised together around Europe, and she knows, we take a

lot of luggage. So yeah, I can't be super helpful with this because I'll just take the whole house and throw it in a bag and go. But I would say... What's a tip that I

can give? I don't know. Sylvia, let's hear from you.

Sylvia Longmire: I'm the opposite. I went to, I'll go a whole week in a carry on, no problem. For

me, for instance, getting into and out of pants is very, very challenging. And I'm in a chair, I won't take a shower. I'll be the first one to say, I don't take a shower every day when I travel. I'm not sweating, and I don't travel in the summers usually. So, I usually travel when it's nice and cool. So, I will wear pants that I can sleep in or wear twice. I wear a lot of black and just mix and match the tops. If I'm going somewhere cold, I'll wear t-shirts under my sweaters or my

 $turtlenecks, so that \ way \ I'm \ changing \ out \ the \ T-shirts \ which \ take \ up \ less \ space,$

but I can reuse the turtleneck. So that takes up less space.

I'll wear maybe one pair of shoes for the whole trip, and I'll wear those on my feet, and I roll up my clothes, so that takes up a lot less space. If I'm going on a cruise, I will bring makeup because you dress up depending on the cruise line and stuff. But if I'm doing a land trip or something, unless it's for a paid press trip where I'm doing a lot more video, a lot more media, stuff that's a little more formal and stuff, then I'll bring makeup. But if it's just for personal recreational, I won't bring makeup. So that's one less mirror I got to bring one, one less bag I got to bring. So, the shoes take up the most space, so one pair of shoes I can usually get away with when I travel. And then just leggings and clothes that I can

sleep in and rolling up my clothes.

Mindy Henderson: Okay. I will tell you, for the trips I have coming up, I'm going to try packing cubes. I've never tried them before, but they look like these great little space

savers, so I'm going to try that out.

Sylvia Longmire: All right, good luck.

Mindy Henderson: Yeah. I've got one more question for you, but while we're asking this last

question, if anyone in the audience has a question for Cory or Sylvia, there is an icon at the bottom of your screen that looks like a little hand, just click that button and that will show us that you've got a question and we'll try and get to

you.

So, my last question is, do you have any travel tips for saving money, getting the best travel deals, airfare, hotel rates? Do you use certain websites, things like

that?

Cory Lee: Yeah, so I think air travel is the most expensive part of traveling, and for me

anyway. So, if I can find a really cheap airfare deal, then that often determines where I'm going to travel to. So, I use sites like... Skyscanner is a really good one.

Sylvia Longmire: Skyscanner is love.

Cory Lee: Yeah, Skyscanner is awesome. You can go in there and actually just put where

you're traveling from. So, for me it would be Atlanta, and then where are you traveling to, you can put Everywhere, and it will give you the cheapest flights from Atlanta to everywhere around the world. And it sorts them from cheapest to most expensive. And so, if I'm just thinking, "Well, I kind of want to travel somewhere in November, but I don't know where exactly," I'll just go on there and put Atlanta to Everywhere in November. And then if I see it's really cheap to go to Costa Rica in November, then I may book that trip and search further. So,

flights often determine where I'm going, I would say

Sylvia Longmire: That's how I ended up in China. It was like \$387 round trip from Orlando to

Shanghai.

Mindy Henderson: What? Oh my gosh. Okay. Fantastic.

It looks like we have one question. Rebecca, do you want to unmute yourself

and ask a question?

Rebecca: I was just wondering what has been each of your absolute favorite places to

travel?

Cory Lee: For me, I would say that it's probably a two-way tie between Morocco and India.

I think that they were both so different than anywhere else that I've ever been internationally and, in the US, especially. So, India was like sensory overload.

The food, the smells, the sounds, amazing, just incredible.

And then Morocco, I went to Morocco with very, very little expectations and wasn't really sure what to expect. It wasn't necessarily a place that I dreamed about going to forever. And then when I actually went, it blew me away. And

when I was in the Sahara Desert on the back of a camel. I mean, just all these wild experiences that I could have never dreamed of. So are two trips that I will like to remember forever.

Mindy Henderson: Awesome. Fantastic. Well, gosh, I am devastated that we're out of time, but you

guys have just been wealth's of information. You've given us great resources. We're going to put all of those in the show notes so that people can access them. We'll put your respective websites and blogs, where it sounds like there are a ton of great resources, in the show notes as well. And I just can't thank you

enough. I've learned a ton and have really enjoyed talking with you.

Cory Lee: Yeah, thanks so much. It was great talking to you.

Sylvia Longmire: Thanks for having us, Mindy.

Mindy Henderson: Thank you. Bye everyone.

Thank you for listening. For more information about the guests, you heard from today, go check them out at mda.org/podcast. And 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 mda.org/quest. If you enjoyed this episode, we'd be grateful if you'd leave a review. Go ahead and hit that subscribe button so we can keep bringing you great content, and maybe share it with a friend or two. Thanks everyone. Until next time, go be the light we all need in this world.