

The Transverse Myelitis Association 'Ask the Expert' Podcast Series
Air Travel with a Disability: Your Rights, Best Practices, and Suggestions

Audio of this podcast is available at <https://tma.org/2C7HCQE>

GG deFiebre:	00:00:00	Hello everyone and welcome to the TMA ask the expert podcast series. Today's podcast is entitled air travel with a disability, your rights best practices and suggestions. My name is GG deFiebre and I will be hosting this podcast. The TMA is a nonprofit focused on support, education, and research of rare neuro-immune disorders. You can learn more about us on our website at myelitis.org . This podcast is being recorded and will be made available on the TMA website for download and via iTunes. During the call, if you have any additional questions, you can send a message through the chat option available with GotoWebinar. We want to thank the sponsor of this month's podcast, Alexion. Alexion is a global biopharmaceutical company focused on serving patients with severe and rare disorders through the innovation, development, and commercialization of life-transforming therapeutic products. Their goal to deliver medical breakthroughs where none currently exists is driven by the knowledge that people's lives depend on their work.
GG deFiebre:	00:01:03	For today's podcast, we are pleased to be joined by Anjali Forber-Pratt, Kimberly Beer, and Bernadette Mauro. Anjali is an assistant professor at the Department of Human and Organizational Development at Vanderbilt University. Her research agenda adopts associated social-ecological model framework and look, looks at issues surrounding identity equity and empowerment through methodology for individuals who are different in some way with a large focus on disability. She completed her degrees at the University of Illinois. Outside of the academy, Dr. Forber-Pratt was also a member of Team USA at the 2008 and 2012 Paralympic Games. Dr. Forber-Pratt acquired transverse myelitis as an infant. Dr. Fober-Pratt coauthored and educational kids coloring book about Disabled Sports titled "Color Learn & Play: All About Sports for Athletes with Physical Disabilities". Kimberly Beer serves as director of public policy for the Christopher and Dana Reeve Foundation. As director, Kimberly assists in advancing Reeve's legislative and advocacy agenda on Capitol Hill and with federal agencies focusing on increasing awareness about paralysis, increasing federal funding for the paralysis resource center, and ensuring access to care for those impacted by paralysis.
GG deFiebre:	00:02:19	Kimberly received a Bachelor of Arts in politics and Spanish from the Catholic University of America, a Master of Arts in Counseling Psychology from Argosy University's Professional School of Psychology and completed two post-graduate Certificate Programs at the Johns Hopkins University in Clinical

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Community Counseling and Counseling At Risk Youth. Bernadette Mauro has worked for the Christopher & Dana Reeve Foundation since the inception of the Paralysis Resource Center (PRC) in 2002. Bernadette manages the Reeve Foundation's information specialists who are the pulse of the PRC. As the director of information and resources, she and the information specialists address the needs of individuals living with paralysis, their family members and their caregivers, and provide individualized support by helping them navigate the vast amount of information and services available to them. Bernadette spearheads the content development for the PRC's patient education materials and the website along with managing the military and veteran's program and its advisory council. Welcome and thank you all for joining us today.

- Bernadette: 00:03:23 Thank you so much. We're excited to be here.
- GG deFiebre: 00:03:28 Thanks. So to start, Anjali and Bernadette, can you please just tell us a little bit about your experiences traveling by airplane?
- Anjali: 00:03:39 Absolutely. I'll start us off. So as, as was said, I use a manual wheelchair, um, due to transverse myelitis that I got when I was a baby. And I travel extensively, as in almost once a week, and this is both domestically as well as internationally. And to put it into perspective, I have already logged over 75,000 miles this year alone, and it's only September.
- GG deFiebre: 00:04:09 Wow, thank you. And Bernadette?
- Bernadette: 00:04:16 I tend to travel professionally, to and from conferences. I've traveled with a spinal cord injury, both being ambulatory as well as now using a power assist wheelchair. I make about six trips per year and I've had varying experiences. Um, but what I always do when I start my trip is read the website on the airlines and find out what their guidelines are for somebody with a disability, what specific information they may want from me. And then my next step is to contact TSA to provide backup support for my traveling.
- GG deFiebre: 00:04:58 Okay, great. Thank you both. Clearly you both have a lot of experience with traveling, so I look forward to talking about these issues today. So to start, can you just walk us through the process of traveling. So you know, from buying a ticket to the end of, you know, getting off the plane and getting your bags and getting where you need to go. Anjali, do you mind starting?

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- Anjali: 00:05:23 Sure. Happy to. So for me, when I book my ticket, it depends whether I'm booking directly through the airline or whether I have to book through my company's travel agent. So, I'm going to talk about both processes because for adults that may be something that um, that is important to note because the process is slightly different. So if I am booking directly through the airline, I tend to use the actual airline's website directly. Um, and mainly that's a personal choice because I'm more familiar with where to find that disability information and to add that information into my record. And unfortunately sometimes with third party sites like Travelocity and Orbitz and things like that, sometimes that information, which is critically important, does not get carried over. If, if you choose to book through those, it just means there's that additional step of then having to call the airline directly, um, as well. And whereas by booking directly through the airline website, most of the major airlines that then triggers them to call you or contact you in order to verify that the information that you put in, in terms of any type of special requests, um, are, are set. So for me, I indicate that I'm traveling with a manual wheelchair, um, and then they ask whether it's a rigid frame or a collapsible frame or folding frame. They also have an option if, if you are traveling with a power chair and they ask specific questions about the type of battery it is and so forth.
- Anjali: 00:06:58 Um, and then the next batch of questions, it has to do with whether or not you are ambulatory. And so whether you are able to walk to your seat, whether you would need an aisle chair, which an aisle chair is a very narrow, um, wheelchair that unfortunately you cannot propel yourself. It has four very small wheels and, and is designed to fit down the, the, um, down the aircraft, aisle-way and um, and so they have to have that on hand if that's something that you need in order to get to your seat. Um, they also ask a question whether or not you can ascend or descend stairs in case you are, like, if you're making a short, shorter commuter flight where they don't always have jet bridges. Certain airports are, um, are known for not having jet bridges for those little commuter flights. And so they have to know that ahead of time because they are able to get a ramp and an elevator type system in place if they know that, that, that would be needed.
- Anjali: 00:07:59 And because of that question, they also typically ask your weight range in case you need to be lifted, if you're not able to self transfer. So those are the, kind of, the bigger batches of questions. Then there's another batch of questions that pertains to me, because I also travel with a service animal, that we're going to talk about a little bit later. Um, so also through that

airline website I answer all of those questions and um, and then go ahead and, and go and book my ticket. Um, and like I said, the airline, if booking through, the airline website will often call you or you can call them directly to confirm all of that information that you put in, which I highly recommend doing no matter what airline you're flying and no matter how often you do fly, um, and that's just to make sure that things go smooth, smoothly or as smoothly as possible once you, um, once your day of travel comes up. For me, then when I get to the, get to the airport itself, again, it's kind of, it you feel like a broken record where you are then rehashing, making sure that everything is set in your reservation and there's specific codes for all of those different pieces, like an aisle chair or needing a wheelchair or needing a person to assist you down to the aircraft door. That gets tied to your reservation, that you as the passenger don't actually see those codes. But it's something that the agents and anyone working for the airlines can log in and see. And so I always make sure at each of those different checkpoints the ticketing counter, if I'm checking baggage, the gate agent, once I get through security, just to make sure, especially if you have a connection. Um, then, um, and, and, uh, I guess I'll talk briefly about going through security as well.

Anjali: 00:09:45 Um, so the, the rules are constantly changing in terms of, um, in terms of going through airport security when traveling with a disability. Um, and I know that Bernadette is going to talk a little bit more about a really great program called TSA Cares. So I'll let her talk a little bit about that. But for me, um, because I travel as often as I do, I do have what's called TSA Precheck, um, which if you are a frequent traveler with a disability, I highly, highly recommend the TSA precheck program. Um, as, what this means is that you actually are able to go through the expedited line, but instead of getting a full body pat down every time you fly, which is the rule, um, if you, if you do not have TSA Precheck or are participating in, in, in these, these, these alternate programs, that they, then they do a visual check of your wheelchair, of any handles, the cushion, and they, um, they, they swab your hands, um, and then you're, you're able to go through.

Anjali: 00:10:48 Um, and then when, when I get to the, uh, to the gate, I again check back in with the agent and make sure that all of the, all of the needs and everything is in the reservation. Um, you are the first to board the plane when you have a disability, so long as they know that you're there ahead of time. So I always like to give them a heads up that I'm there and let them know where I'll be sitting, waiting to board. And they verify the information. An important thing to note is that most airports, they, the

airline themselves are not the ones that actually provide the services of helping you to get on and off of the plane. It's a contracted, each airport contracts out with their own agency. So again, you have to explain yourself again when the contracted company, when those representatives show up to the gate to and, and typically they'll come over and ask you like, "Oh, are you the one that needs the aisle chair?"

Anjali: 00:11:45 And, and then I, and then I confirm, "Yes, I am. I can self transfer myself and this is where I'll be sitting" and, and all of that. And when I get down to the door of the plane, I try to be as proactive as I can. So you get a, I get a gate claim ticket for my wheelchair, so my wheelchair gets stored underneath the plane. Um, and the gate claim ticket means that it will be brought to me at the aircraft door. Some airplanes are able to accommodate a folding wheelchair or a smaller wheelchair in the first class, a larger cabin closet. Um, uh, for me, my chair goes underneath the plane, um, but I would make sure that you take anything that could come off of it. So like cushions, extra padding, anything like that, anything that's loose you want to take off because of the, of how it gets handled and put under the plane and you don't want things to get lost or broken. If there are certain things on your, on your wheelchair that are worth protecting, um, you know, you can put some reinforcements with like a pool noodle or um, some, some tape, things like that to protect from scratches or from potential damage. And I think I'll, I'll hold off there and turn it over to Bernadette to fill in any missing pieces that she experiences on her end.

Bernadette: 00:13:12 I follow a very similar process to Anjali so I am going to go quickly on some of it. I avoid using third party booking, and I have the luxury of not having to do that. So I book my flight directly from the airline. I tend to use one specific airline because I live at a major hub. That way I'm familiar with the airline and their guidelines. I have a frequent flyer number so that when I do travel, everything is already attached to my number and all my specific needs are already in place. Um, so I do mark off a wheelchair user, um, power assist wheelchair, lithium ion batteries because that sets off a whole nother, um, area that you have to address. And I get my ticket. A week before I'm ready to fly, I call the airlines. I confirm that everything is in place. I reiterate that I do need an aisle chair. And then once I arrive... And actually then after I've done everything with the airlines prior to my flight, within 72 hours of flying, I call TSA Cares. I try to do it as far in advance as possible, but they do request a 72 hour call ahead. And TSA Cares can answer your questions about flying, and anything specific to you

disability, if you have a visual impairment, if you're a wheelchair user, if you're hard of hearing, um, or hearing impaired, they can answer the whole slew of questions. And they're also a place to call and compliment somebody who has assisted you quite well or to file a complaint so that TSA can investigate. The, there is an 855 number for TSA Cares, and it is 855-787-2227, and the federal relay number is 711. And they're open from 8:00 AM to 11:00 PM Eastern. And then on holidays from 9am to 8pm.

Bernadette: 00:15:33 And specifically what I ask for is a passenger support specialist. They're not available at every airport, but I always put in a request so that it's tied to my ticket number and my flight times. And if I get up to the TSA line and I have not met with a passenger support specialist, then I just asked for a supervisor. And that supervisor, um, moves me through the TSA line and assists me with any belongings that I may have. Um, and also, um, the advantages often as a female, for female assist, there's a, a prolonged wait. So, um, if I get a passenger assist specialist, if they're female, they can do the pat down. If they're male, they can relieve another female behind the lines and then, um, they, they do the, uh, security screening and then I can move through at a much more rapid pace. Um, it also, if I'm in an airport on my own, then it assists me in making sure that I don't lose my belongings and I don't lose sight of my belongings because the passenger assist specialist accepts responsibility for them.

Bernadette: 00:16:56 Um, after getting through security with boarding, I follow the same steps. I, at every step of the way, I reiterate that I need an aisle chair, and that I will keep my chair until boarding. Um, that my chair again goes under board, under the plane. I stress from the minute I check in my bags that I have power assist wheels because lithium ion has to be transported in a particular manner. Um, I also go to the airline's website and they have a form and that form can be attached to your chair, and you can also carry it with you. So I tend to make two copies. I have them filled in for the entire round trip. And I show them to the gate agent as well as I have them attach it to my chair because it tells them exactly what's on my chair, what I'm taking on board with me and um, how they need to handle my chair.

Bernadette: 00:18:01 The new thing that the airline is asking for is the weight of your chair. Um, so if you're using a power chair, if you check your serial number, you can go online and you can find a basic estimate of the weight of your wheelchair. Um, again, um, manual chair, you can do the same thing using the serial number. One of the things that I've found is very important, and

it speeds things up, is that I have a cinched nylon bag that I remove my arm rest, my side guards, my anti tip, and I pull all the parts to my chair apart or have an airline employee assist me in doing that. And then they are loaded on the plane. As I transfer to the aisle chair, I have them remove my wheelchair cushion and place it on my seat so that by the time I get into the plane, there's no messing around, uh, with my wheelchair cushion.

Bernadette: 00:19:04 It speeds everything up and it makes it much easier. For the lithium ion batteries, they have to be removed and put in a special container, and they have to be removed using a penny. So I always keep extra pennies in my pant pocket and um, I just, the airline I fly has the gate agent help board you, and then they have an outside contractor that does the other portion of it. So I give people specific tasks and I make sure that, you know, they follow the directions. I give them an explanation of how I need to be assisted for transferring and so that makes it smoother. So that about wraps up that portion.

Anjali: 00:20:01 And I just have a couple things to add that made me think about, as Bernadette was talking. First of all, I forgot to say what the slight difference is if I'm booking business travel, which is through my company. We are supposed to use a specific travel agent and I have advocated to make sure that whenever I do booking through my company, that I get the same travel agent so that I don't have to repeat all of my access stuff. So they now have a lot of this information that I'm already providing to the airlines if I were to be booking directly through the airline. Um, so they already have that on hand for me and I just advocated to make sure that, um, that, that was always the person, um, that my, that my bookings get routed through. Um, secondly, I wanted to say that for individuals who may be power chair users, I've seen many individuals do a version of exactly what Bernadette was saying with very clear directions about how to handle the wheelchair and, and, and also some individuals go one step further in terms of the why.

Anjali: 00:20:56 So I have a friend who, um, has given me permission to, to read what he, what he posts on his chair every single time that he flies. Um, which reads, "Please take the most caution with my wheelchair. It is precious to me and without it, my life is very difficult. I'm traveling to have fun and live life and I need my chair to be awesome. Your care and consideration is appreciated. If there are emergencies or questions during landing or takeoff, please call me immediately at (and he lists his number). My chair weighs approximately 300 pounds. Use multiple people to move chair on steep surfaces to prevent it

from falling or running away from you. Runaway wheelchairs are the worst. Please follow the directions below. To push..." and then he has very clear directions that are pertinent to his specific chair. "Put it in neutral so you can push it easily by lifting the lever up in front of the chair next to the left wheelbase and behind the footrest. Two, use handlebars to push from behind or push from the front by pushing from the seat. Three, when finished putting it where you want it, please push the lever back down. To lift, if you need to lift the chair under worst case scenario, please keep it upright. One person can lift from the back, from the very bottom of the chair. One person can lift from the front, at the very bottom of the chair. There are metal handles underneath the footrest that are easy to hold onto. One person from each side can lift the bottom of the chair. Always lift from the base of the chair, never from the seat or footrest. Do not turn the chair on its side or upside down, tip the chair forward or backward, push or pull the chair from the side - it will not go anywhere, put stuff on my chair, attempt to drive the chair with the joystick. Thanks. I appreciate you."

- Anjali: 00:22:30 So that's one example of, of a, of a very detailed, um, sign that, that he, like I said, he travels and put on his chair in multiple places. The other thing that I wanted to point out is that, um, you, you are not, you are not charged for, uh, for medical devices or equipment. So if you're bringing on like that cinch bag that Bernadette was talking about with your, the components of your wheelchair, like the foot rest and cushion and things like that, that's not considered a, a bag that you would be checking in in terms of getting, getting charged for, um, from the airlines so long as it's medical equipment or medical devices. Um, and then lastly I wanted to add as well that if you are ambulatory using a walker or crutches or, or, or even neither of those things, you are still eligible with a disability to pre-board and to get yourself situated, should that be a helpful, a helpful component. Many people like to do this, especially from our community because of fatigue and waiting in the long line, and um, you know, on the steep jet bridge. Whereas if you pre-board, you'll be one of the first to go down to get situated in your seat.
- GG deFiebre: 00:23:43 Great. Thank you.
- Bernadette: 00:23:47 Can I also add very quickly, is that I ask the individual who is going to be loading my chair onto the plane to come up and speak with me briefly. I've had my chair damaged a number of times, and I have found that this is the best deterrent. I let them know that my chair are my legs and that it's incredibly

important that it arrived in one piece. The other thing that I've added and that's prevented multiple damage on my last few trips, is that I fold down my wheelchair back, the rest of my life rigid, but I use a bungee cord and that holds the back in place. It prevents the individual boarding my chair onto the plane from opening it and moving things. I've had them inadvertently take the back rest off, and then it not go back in place. I've had them try to remove wheels, and then when I got into the chair and started wheeling, the wheel fell off on me. So by talking to them and being very clear that my chair must stay in an upright position, it cannot go on the side, on the wheels. I've prevented additional damage to my chair. So that is one small key piece and I always express gratefulness and I'm courteous when I talk to them and they're always very respect.

GG deFiebre: 00:25:17 Those are all great pointers. Also, just to add with the power chair, Anjali, thank you so much for reading, you know, that detailed note. When I've traveled with a power chair, I've actually put tags on the places where I want them to lift the chair from because as, as you noted, Anjali, lifting it from the seat can, can mess up the chair. So I've, I've done that as well. And also I've wrapped bubble wrap around the joystick area, so that, you know, and then removed the power so that they can't, it doesn't turn on in the middle of the, of the plane. But yes, thank you both so much. It was really detailed and we really appreciate it. And then in terms of, just mentioning, you know, getting off the plane, do you mind just talking a little bit about, you know, how it is? Is it the same sort of situation as getting on?

Anjali: 00:26:07 So it's almost the same, but it's in reverse. So you're the first on the plane when it's time to leave but you're the last off the plane when it's time to get off, is kind of how that works. So they do have you wait until everybody else has deplaned and then they get the same special assistance that you had requested previously. I tend to remind the flight attendant as we're getting ready to approach for landing, especially if I have a connection or something like that. Um, so that there is a reminder for them that they, that they have a person who needs an aisle chair on board and all of that. Um, so that's, that's really the, to me, the only biggest, biggest difference. If you need it, they will also escort you from the, if you have a connection, from that connecting gate to your next gate, should that be something that would be helpful in terms of managing your, your, um, your bags or needing, needing assistance being pushed or something like that through, through the airport. That's not something that I take advantage of but that is something that you, that you are able to request.

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- Bernadette: 00:27:15 What I'd add to that, because my chair is taken apart, and the power assist is removed, if I have a tight connecting flight, I do request somebody to push me through and to assist us getting through to the next flight. I've had as short of time as 45 minutes. And when you're the last one off and you're not quite sure where you're going, it just doesn't make sense to reassemble my chair and then take it apart again when I reach my destination of the next gate. So I have asked for assistance in those situations. The other thing is when I get off, it is, it's just in reverse, but again, I will designate and ask people very clearly to assist me in assembling my chair back together, um, versus taking it apart. I can take many of the pieces apart very easily, but reassembling it is more difficult. So I just hand them the pieces. I stay in the aisle chair. The other thing that I have started asking is that they not allow people to come down the gate walkway until I've gotten out of the aisle chair and back into my wheelchair. I've had that happen on a couple of occasions and um, I find it dangerous because I'm, I'm in the middle of the walkway and I just ask them to halt or to not let people in and board early until I'm in my wheelchair.
- GG deFiebre: 00:28:58 Thank you. And, Anjali, do you mind talking a little bit about, I know you mentioned you travel with a service animal. Do you mind talking a little bit about your experience with that and any tips or pointers you have?
- Anjali: 00:29:09 Absolutely. I'll try to keep this brief as that could be a whole topic in and of itself. Um, but I do travel with a service animal. His name is Kolton and on social media he's affectionately hashtag KingKolton. And he is able to help me with mobility and so picking things up that I drop and able to help pull me through the airport and things, things like that. Um, and there've been a lot of changes that are underway with airline policies as well as um, pending changes with the Air Carrier Access Act that I know Kim is going to talk about it in a little bit. In terms of traveling with a service dog, there's basically the same way that you're advocating for all of the different pieces, um, about your mobility needs and your access on and off the plane, I also have to advocate for Kolton. And so, um, some of that involves making sure that they know ahead of time that I'm traveling with a service dog. They are allowed to ask what skills he is trained to perform to help me. They are not able to ask specifics about your diagnosis or your, the, your actual disability itself. Um, and they are, they do also ask the weight of the dog and that's important in terms of weight and balances, that weight and balance for the airplane. So I do provide that information ahead of time.

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- Anjali: 00:30:32 In terms of, um, of some other considerations. Um, I tend to look up or, and I keep a list in my phone, of airports that have pet or service animal relief areas inside the airport beyond airport security. It used to be that you had to actually leave the airport in order to toilet your dog. Um, there have been some legislative changes that are, um, that airports that serve, I think it's over 10,000 passengers a day are required to have an inside relief area, um, after security. Not all airports are yet in compliance with this, but more and more are popping up. Um, and so that helps me to plan my travel. So for example, there's certain airports that I like to have connections through because there's multiple, um, relief areas. So depending on which gate that I'm, that I'm transferring at, um, I know I already know where they are and, and, um, and things like that.
- Anjali: 00:31:23 Um, the rules in terms of on the plane is that your dog is working and so the same way that you're, you're, the service animal is not interacting with people around them, that the same applies on the plane. He is trained to curl up under the seat in front of me and, and he is not allowed to encroach on other people's space. Um, we have very rarely ran into any issues with that. Um, although this past weekend we had an issue where there was another individual with a dog on, on the flight and there was some confusion on whether it was a service dog or an emotional support animal or a pet. Um, there was all kinds of confusion and the airline workers were concerned that my dog wasn't going to be okay being around other dogs, which I then explained to them no, like he's a trained service animal, he's fine, you know, and, and all of that. So again, it was just taking the time to try to educate and to, um, and to work through the, work through the situation. Hopefully that covers enough.
- GG deFiebre: 00:32:27 Yes, that was very helpful. Thank you. Um, and for our next question, um, Bernadette, do you have any tips for preventing pressure sores while on the plane?
- Bernadette: 00:32:41 What I do when I'm on the plane is, the first and foremost is that I make sure that my wheelchair cushion is put onto my seat. And I double check that it's on properly, um, so that the front is facing forward and not reversed. And then during the course of the flight, um, I, I do pressure shifts. I will, you know, lean forward, I will lean to the right, I will lean to the left and I try to do it on a regular basis. Um, the long flights are difficult, um, because if you fall asleep you obviously don't do your pressure shifts. Uh, so I do use my phone with the timer to make sure that I remind myself and it goes off at set intervals. And it's by vibration so that I know that it's there but it doesn't

disturb anybody else. So um, that's a process I do, and just for safety. I set a timer just to remind so that if I do fall asleep it wakes me up and I shift.

- Anjali: 00:34:03 One thing to add, and my process is fairly similar in terms of making sure that I'm doing pressure releases. One thing that I've noticed, and I've only ever had one, thankfully, only had one pressure sore from flying before, but it was not in the way that you would have necessarily anticipated. Um, so in bulkhead seats, which are sometimes more towards the front of the plane and you don't, you don't typically have a space, you don't typically have a seat in front of you to put belongings. So it's like that wall. So because there's the wall sort of on the airplane, the seatbelt mechanism is a little bit different as are the armrests. So instead of armrests that go up and all of that, it's a more rigid, solid seat on either side of your hips and the seatbelt itself is, is a little bit bigger because it has a sort of a, um, I think it's your, your, um, uh, for safety mechanism if there were to be an accident. And what happened to me was that I ended up getting, um, a pressure sore on the side of my leg from that larger seatbelt. Um, and it was a long flight, um, that, that, uh, that, uh, very similar to what Bernadette was describing, I didn't realize that it was happening. I was doing my other pressure releases, but just didn't realize that, that, that, um, that, that, that mechanism against that solid side was causing an issue. So just something to look out for.
- GG deFiebre: 00:35:30 Right, right. That's good to know.
- Bernadette: 00:35:35 What I'd also add real briefly, is that I put a lot of consideration into what I'm going to wear when I'm, when I'm flying. I may wear jeans during the day at home or when I have more opportunity to, to shift and move about. But when I'm flying, I make sure that I wear something that is without pockets, especially in the back, so I have no additional pressure that makes difficult.
- GG deFiebre: 00:36:11 Yes, that's a good tip as well. So, when I started traveling again after needing to use a wheelchair, I wasn't sure how I would do this. Um, so what happens if you need to use the bathroom when you're on the airplane and you're not able to get up or you have issues with moving around?
- Anjali: 00:36:30 Um, I can start. Um, so the, my answer to this is going to vary based on if you are a guy versus if you are a girl and also whether it's a shorter domestic flight versus a longer flight or an international flight. So to, so to start off, if you are a guy who catheterizes, um, I have certainly witnessed many teammates

and friends of mine who just requested one of the airport blankets and they will cath into a bottle right there in their seat. And I'm always very jealous of that because that's not something that I, as a girl, am able to do in my, in my seat. And there's also some guys who may not be comfortable with that. So just, just throwing that one out there. Um, in terms of a shorter flight, there's unfortunately not really anything that, um, that typically can be done if you, if you're not ambulatory on, on the flight.

Anjali: 00:37:26 And in dire emergencies I have, um, I have actually crawled to the bathroom, um, in that type of situation. There, sometimes individuals that I know will travel with, um, with a Foley cath or a leg bag for flights for that reason. Um, I try to plan my toileting schedule around, um, around my flights, and so making sure that I'm going right before I board and, and trying to make sure that I have a long enough connection to be able to, to stop at the restroom before, before boarding my next flight. Kim, I'm going to have to defer to you because I cannot remember what the, how long the flight has to be before they are required to have an aisle chair on board. I want to say it's flights more than four hours, but I'm not positive on that. Do you happen to know?

Kim Beer: 00:38:23 Well, I can tell you that the Air Carrier Access Act, which I'll talk about in a little bit, requires that one lavatory on each double aisle airplane must be accessible to a passenger using an onboard wheelchair. So I don't think the time actually is relevant. The problem is on single aisle airplanes that, um, that they do not have accessible, uh, lavatories and they do not have to, the airline does not have to provide accessible lavatories for, um, single aisle airplanes, which is the majority of commercial airlines. And I'm sure in your experience what you're describing, it's so horrendous. And an organization, Paralyzed Veterans of America, has actually filed a lawsuit suing the Department of Transportation for delaying the regulations that would improve and require single aisle airplanes to have an accessible lavatory. And so currently they're in the beginning stages of a lawsuit with the Department of Transportation. So these are areas in which advocacy organizations are trying to improve this. And I've not, I've heard one, but hundreds, I've read hundreds of stories that Anjali just talked about, crawling to use the restroom. The indignity of flying shouldn't, should... I mean the dignity, everyone should have the dignity of flying and using a restroom. So this is something that we're taking very seriously and um, and there are ways in which you can file your complaints to the Department of Transportation, especially around traveling and using lavatories. Hope that helps.

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- Anjali: 00:39:52 Yeah. Yeah, and I think, that makes sense, and whereas most of the, I guess, the longer flights tend to have, tend to be that, that double aisle aircraft. So I think you're right, it doesn't, it doesn't pertain to the length of the flight but rather the type of aircraft being used. Um, but with international flights they are generally two, um, two aisle planes. And so with those ones I do advocate ahead of time to make sure, and I want to see, like personally with my own eyes, the fact that that aisle chair is the onboard aisle chair, because it is a little bit different than the aisle chair that you use, um, that you use typically in the United States getting on and off of the plane. And so, um, just to like, so basically it's a, it's a folding version of an aisle chair and it's a sling seat instead of a harder seat. So, um, it does make the transfer a little bit different from what you might be used to and, and so forth. Um, but I like to make sure that I physically set eyes on it and that I know that there's a plan in place where every flight attendant on that plane knows that if I need to use the restroom, that, that I'm going to need to use that.
- Bernadette: 00:41:04 If I could add quickly, one of the considerations is that you're the first on, you're the last off, and you have to take weather into consideration. So you may actually be delayed on your plane. So always, my advice is to allow yourself a lot of extra time. I tend to pad by almost two additional hours.
- GG deFiebre: 00:41:35 Thank you so much. That's good advice. Um, so, uh, there's often a concern that an airline might damage a wheelchair. Um, what happens if your wheelchair is damaged by the airline?
Anjali?
- Anjali: 00:41:55 Sure. So first and foremost, you want to do a, do a visual check and an inspection of your chair before you leave the airport. So that's probably the biggest thing is that you don't want to wait until you've gotten back to the hotel or back home or whatever that is for you to do that once over because there are, there's paperwork and things that has to get filled out while you are still on the premises. Um, you do not... So if, if you originate, say I live in Nashville, so if I originate here in Nashville and I'm flying, I'm flying to DC and I'm flying through Charlotte, um, if the damage happens from Nashville to Charlotte, you are allowed to wait until you get to DC in that example. So to your final destination and then doing it, so you wouldn't have to necessarily fill it out there in Charlotte, but it's just so long as it's within, within that, that singular trip that you, that you are on, that you're filling out the paperwork. So typically you would go to the airline that you were traveling and, and explain to them that your wheelchair was damaged and that you need to fill out a claim. Um, and um, and so you fill it out and you take pictures

very similar to if you are in a car accident and you have to fill it out with your, fill out that information with your insurance company. It's a very similar process to documenting the damage and what happened, um, on your, on your wheelchair. Um, they, they then are, they then send out an adjuster if it's over a certain dollar amount and, and all of that. Um, and, and they, you are eligible to get, um, to get a rental type of a situation or, or, um, or, uh, additional equipment, although that is a, that is a process that doesn't always go as the way it's supposed to go, so to speak.

Anjali: 00:43:43 Um, and, and so the best thing that you can do is to be as much of an advocate as you can. And I would also say in addition to reporting it with the airline itself, um, I would encourage anyone who experiences that type of issue or any issues with these processes to also file an air travel complaint with the US Department of Transportation. And the reason for filling it out, even though the airline is the one that's ultimately responsible for that damage, is that the US Department of, excuse me, the US Department of Transportation actually tracks this type of information and the only way to really help to push for improvements on policy and some of the things that Kim was talking about is to be able to show that there are people with disabilities who are traveling who are experiencing these issues such as damaged wheelchairs. And so if it's not reported it, it is misconstrued as the fact that this doesn't happen. And so that's the importance of filing in both places through the US Department of Transportation as well as through the airline.

GG deFiebre: 00:44:46 Great. Thank you. Bernadette, do you have anything to add? Or Kim?

Bernadette: 00:44:52 I can add that I have had damage done to my chair. and I have found the airline very receptive. I filed a complaint immediately, and in almost every single case, before I've even gotten out of the airport to my destination, I've had a call from the company that's responsible for the repairs trying to set up an appointment. So, um, it's one of those unfortunate parts of travel, but again, as I've indicated, if you learn how to streamline your chair and you instruct the people who are boarding it and unboarding it as well as, um, for me, the biggest change has been using the bungee cord to hold the seat back down. That's eliminated the majority of the damage, and any damage I've had has been minor and cosmetic, um, and that I've just let go. But it has prevented the, the backs from being broken on my chair and other things like that. So definitely follow through the process. Be clear on your rights. You need to make sure that they, I've had them try to file as a lost bag and

you have to stress that it's - because there's a separate claim for damaged medical equipment, and you make sure that they file the form appropriately. Do not sign it until you've read the form completely. If there is something missing that you think is important, please add it in.

GG deFiebre: 00:46:44 Thank you. I think for now, we can turn it over to Kim for a little bit since we're talking about some of this legislative, you know, the rights that you have when flying. We can turn it over to Kim for a little bit to talk about the laws and stuff that's upcoming?

Kim Beer: 00:47:00 Sure. I had been with the Foundation a little over a year and a half and I was unaware that the American with Disabilities Act, the ADA does not apply to commercial air travel in the United States. In fact, a law was passed in 1986 called the Air Carrier Access Act, otherwise known as the ACAA. We love acronyms here in Washington. This law was passed to make it illegal for airlines to discriminate against passengers because of their disability. And the Department of Transportation, as we've been talking about throughout the podcast, is responsible for enforcing the ACAA, which applies to all flights to, from, or within the United States. Airlines are required to provide passengers with disabilities many types of assistance, many of which Anjali and Bernadette were talking about including wheelchair, other guided assistance to board the plane or connect to another flight. Feeding accommodation assistance that meets passengers' disability-related needs and assistance with the loading and stowing of assistive devices. And as they have talked about, and I'm sure you've all experienced, those listening, this doesn't always go the way it should. And so as Anjali stated before, really filing your complaints with the Department of Transportation, last year alone over 30,000 were filed. And as a result, several senators have introduced legislation called the Air Carrier Access Amendments Act to improve air travel for people with disabilities. And so currently, those amendments would provide a very specific passenger Bill of Rights. It would, it strengthens the enforcement to include, as I mentioned, protections of the rights of passengers with disabilities and the private right of action. It would ensure that airplanes are designed to accommodate people with disabilities and airlines meet accessibility standards, including safe and effective boarding and deplaning, visually accessible announcements, and better stowage options for assistive devices. It would improve access to seating accommodations and it would close service gaps and air travel for passengers with disabilities. So currently, another piece of legislation that oversees federal aviation is called the FAA Reauthorization Act, and that currently funds all travel in the United States. And that

expires at the end of the month. These amendments that I just talked about that the senators have introduced to improve air travel is currently being debated to be included in the FAA Reauthorization, and currently Congress has about seven legislative days if I'm counting correctly in order to ensure that FAA funding continues. And so we're working with many advocacy groups to make sure that these, these improvements are included in the FAA. So I'll be sure that I can send along after the podcast ways in which you can get involved to contact your senator and your House, your member of Congress to ensure that they know that you're living in a community, living with a disability, and that you want to make sure that these improvements are included in the ACA Amendments Act.

GG deFiebre: 00:50:12 That'd be great, thank you.

Kim Beer: 00:50:15 Sure.

Anjali: 00:50:17 One thing to add to that is that, um, there's also, through the US Department of Transportation, there's a toll free hotline for air travelers with disabilities. So if you experience issues or have a question about your rights, um, or, or an immediate nature, um, there's, there's a toll free number, which I'll say here, but then we'll also make sure that it gets posted with this podcast. So that number that I keep in my phone in case of any type of emergencies is 1-800-778-4838, and that's the voice number. Um, and they're also a great resource. And on, on the same website for the US Department of Transportation, that's also where they have the DOT air travel complaint form that I was talking about, which is separate from a complaint form that would go to an airline directly.

Kim Beer: 00:51:17 This is Kim. I think Anjali and Bernadette may have referenced this, and apologies if you have already talked about it. The Complaints Resolution Official, the CRO? Have you all talked about that?

Anjali: 00:51:23 No, go ahead.

Kim Beer: 00:51:26 Well, you probably have had personal experience with it. But all airlines are required to have a CRO immediately available, even by phone to resolve disagreements should you believe that your rights are not being enforced properly or you have a question about that. And you're entitled to talk with a CRO who has authority to resolve these complaints on behalf of the airlines. I don't know if Anjali or Bernadette has specific experience with that, but I just wanted to make sure that those who are listening know that that is also their right.

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- GG deFiebre: 00:51:55 Great thank you. These are really great resources to have on hand when traveling. Going back to a more specific question from our community - we had someone ask, you know, they were diagnosed with NMOSD and they want to go traveling internationally and they were advised to find out names and contact details of experts within that, you know, that see patients with NMO in the places that they want to visit. Um, so one, how does someone find out the local experts and then you know, or is it just better to stick with domestic travel? Anjali?
- Anjali: 00:52:38 Yeah. So first of all I would say take a look at some of the awesome resources from the TMA in order to find a doctor, and GG you might be able to, to, to direct us to specifically where on the site that is. Um, but we do a really good job at keeping a list of doctors who specialize in these rare conditions. Um, and, and that is a worldwide database, um, that the TMA keeps. Um, and so that would be one piece that I would say in terms of how to find somebody. Um, I would also say that specifically with international travel, I tend to find it's always a good idea, especially if I'm going somewhere that's a little bit more remote, I tend to give my, whether it's my transverse myelitis doctor or my primary care doctor, a heads up that, hey, I'm going to be in Zambia and hopefully there's not an issue, but if there is like, I just want you to know that I am going to be out of the country and that I might need some help, should something, should, something come up. So I've had more luck with leveraging my contacts with the doctors that I have relationships with and giving them that heads up that hey, I'm going to be in this situation and let's hope that we don't need to tap into that resource. But that's been more of my approach instead of constantly finding a doctor in some of these places that I go and I think part of that is because I travel as much as I do.
- GG deFiebre: 00:53:58 Right. Right. And you know, thank you, Anjali, for pointing out the Medical Professional Network on the TMA website. I would also say just in general, you know, if you, if you're somewhere and you are, you know, really need assistance finding it, a multiple sclerosis center is usually a good bet as well. But being in contact with your primary care provider or your local doctors at home to let them know you're traveling and also get their advice for if anything is needed, you know, when you're traveling, if you need an extra prescription, you know, more medication or something that's always a good idea as well.
- Anjali: 00:54:31 And also particularly related to international travel, some countries because the, a lot of the rules that, that Kimberly was talking about in terms of the Air Carrier Access Act, um, some of, some of these don't apply in certain other countries. And so

some airlines internationally, they actually require you to have a letter by, signed by your MD that says that you are medically stable and cleared to fly. So I, so again, this is only when I go internationally. That's the other reason why I also tend to give my doctor a heads up because I'm already going to be asking them for that letter just to have in case I need it. Um, and, and I have been asked to, to present it before, um, but, but so a lot of times it's more of my own assurance to have that letter. And then I also know that should, should an issue come up, that they already have documentation that they knew that I was traveling.

GG deFiebre: 00:55:22 Right, right. Good advice as well. And then we just have a few minutes left. Um, I did, you know, we did talk a little bit about airlines damaging wheelchairs. We didn't talk about them losing wheelchairs. I mean, this personally happened to me recently, where my wheelchair was lost for over an hour at the airport. And I've heard of this happening to other people, or it gets, a wheelchair gets left if there's a connecting flight or it just gets left in the originating airport. Do you have any tips or suggestions for dealing with that, or has that happened to you?

Anjali: 00:55:57 Sadly, it has. Um, for me, I tend to, I tend to try to be paying attention as much as I possibly can during the boarding process, and so I'm actually looking out the window to like see them taking my chair down. And if I see, if I'm watching and watching and watching and I don't see it happening, I'm the one that's ringing that call attendant button and, and trying to intervene before we actually start moving. Um, that's, that's something that I try to do. Um, of course there are certain situations where you're not able, you know, you don't have that good line of sight out the window or you're sitting on the wrong side of the plane, you know, or something along those lines. Um, and so it is, it unfortunately can and does happen, although I wouldn't say that it happens super, super frequently, especially if you're advocating as much as you, as you can at every step along the way.

Anjali: 00:56:50 I think that's probably the biggest thing to remember when we started this podcast is that you're, you are going to feel like a broken record, having to share the same information so many times again, time and time again. But you have to remember that the person that you talked to at the ticketing counter is different than the person you talked to at the reservations and is different than the gate agent and is different than the flight attendant. And so even though it feels like a broken record, just that self advocacy piece is huge and I don't want our community to think that it's not insurmountable. Like, you know, we can

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and do travel, and this is just one of the ways that we have to be strong advocates for ourselves.

GG deFiebre: 00:57:34 Great. Thank you. Bernadette, do you have anything to add?

Bernadette: 00:57:38 The only incident that I had was one time as they were taking me off the flight, the people that pick up other passengers with wheelchairs was using my personal wheelchair to take somebody away in, and I was able to stop it. Um, so after that I make sure that my name, is on, it's underneath where my seat cushion is with a piece of tape and says private property. Um, and then with my name on it. Just so that I don't have my chair taken away again. Uh, I've, I've heard of other people losing their chairs and then they've seen somebody else being pushed in the airport. So that's a simple one I think to avoid by just making sure that your name is on your chair or it's very visible. Um, because once you strip it down it looks like any, it can look like any chair. So that would be my main piece of advice,

GG deFiebre: 00:58:49 Right, and Anjali, I know you mentioned making sure there is a baggage tag, you know, a tag that you get at the gate for the wheelchair, which is I think also really important for not losing it as well.

Anjali: 00:58:55 Yeah, yeah. And you just want to make sure that, you know, if it's domestic, that it's a gate claim ticket, not a baggage claim ticket because if it's a baggage claim ticket, it's going to go to the conveyor belt and then you will be without your wheelchair at the door of the plane. So learning those differences between those tags and so forth. And one thing to add is that, again, going back to, you know, differences between domestic and international. When you're international, very few places will allow you to bring your own personal wheelchair to the door of the aircraft. Um, some cases you're able to do it like on the way to that country, but not when you leave because you're originating with the laws within that particular country. Um, and so then you, then you do have to use the, the, um, the airport chairs in order to get reconnected with your bags. One tip on that, is that I then, when I, when you reclaim your checked bags at customs, that's when you hopefully get reunited with your wheelchair, and then I just tear, tear the baggage claim tag off of my wheelchair at that point and then I go back to my own process of the gate claim tags. So I sort of play a fast one on them at customs.

GG deFiebre: 01:00:09 Right, right. Good tips as well. Well we're at the end of our hour. I know we could, we could do this podcast again for much longer and I hope we can continue the conversation, you know,

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in a future podcast. But I wanted to thank you three so much for joining us today. There's some really good tips, so we really appreciate it.

Kim Beer:	01:00:30	Thank you.
Bernadette:	01:00:33	Thank you.
Anjali:	01:00:34	Thanks so much.
GG deFiebre:	01:00:36	Thank you. Bye.