

Air Travel Stories from People Living with ALS

Cynequa Smith	
First Name	Cynequa
Last Name	Smith
Municipality	Rich township
State	Illinois
Comment	I was so excited to fly with the Batmobile (my electric wheelchair). Every time we have flown together (only 2 times), the Batmobile was damaged. A piece missing here. A piece missing there and so on.I wish this would not happen. My Batmobile is a lifeline to keeping me connected, keeping me involved in the community and my ability to travel..

Mr. John Werner	
First Name	John
Last Name	Werner
Municipality	North Heidelberg township
State	Pennsylvania
Comment	I have Als but do not yet need battery powered wheel chair. The problem begins with the air ports that need to be able to lift the chair onto the plane. The plane needs aisles at least 36 inches wide then an area to park the wheel chair patient.

Julie Van Dusen	
First Name	Julie
Last Name	Van Dusen
Municipality	South Rock Island township
State	Illinois
Comment	I work in healthcare and I travel often. Every time I fly, there is an issue with my chair, my seat assignment, or the process of getting checked in to the process of getting my chair getting back to me. Out of the 4 times I have recently flown, my chair was damaged 3 times with one being a total replacement of the Permobil M3 coming in at a loss for the airline at \$49,500. For me though, it's about the indignity, stress, and not having the ability to move safely and comfortably. My chair has been left on the tarmac in the rain for 8 hours because there was insufficient staff to load it to my connecting flight. The baggage supervisor apologized profusely, but it didn't resolve the issue of me not having a chair. I was stranded

Air Travel Stories from People Living with ALS

in the New Orleans airport for 10 hours waiting for the chair to come on another flight only to find out that it didn't work. The airline offered to call me a cab to wait at my hotel. When I asked them if someone was coming with me to carry me from the cab to my room, they looked at me blankly. When I asked if I could take an airport manual chair for the night, they said no. I asked for a rental and they said they couldn't get on at this hour so I waited at the airport only to receive a wet chair that didn't work. We ended up unlocking the brakes and pushed the chair onto an airport shuttle. I rented a chair on my own the next day as I was leaving on a 7 day cruise. The last two times I flew, my control was broke, a chunk was taken out of my rubber wheel, one wheel cap and a shroud was missing. My seat was leaned back during loading and I think they put the tie down straps over the entire chair because the back to my seat was bent, needing repair. I've had 3 rolling walkers replaced in the past two years due to handles being snapped off, brakes bent, wheels crushed, or I was unable to unfold it entirely because it was smashed. I'd also like to speak about the practice of up charging to obtain a seat. I am still able to take small steps with assistance and need a chair toward the front. I have never asked for first class, but I do ask prior to the travel date to be assigned near the front only to arrive to find out that I've been assigned the very LAST row, not reassigned at all or assigned to the very FIRST row with fixed arm rests that prevent the option of sliding into a seat. Even if I did choose to use their aisle chair to get me to my seat (I NEVER would because I don't trust their ability to move a person), how am I supposed to slide into a seat if the arms are fixed? I flew from Chicago to San Diego last month for a physician conference and was denied a seat change. On the return, I had to wait at the gate while the attendant called everyone up in the three rows behind me asking each one if they would mind moving forward to the first row. Each one looked me up and down and by the time they got to the 5th person who thankfully agreed, I was beyond humiliated. So you may ask, why would a person travel so often if it is so troublesome or maybe you are wondering why I just don't

Air Travel Stories from People Living with ALS

buy a first class ticket every time? I travel because I have the right and ability to do so. And, even though I can afford to purchase a first class ticket or a seat with more room, I don't based on principal alone. Not everyone who needs a seat near the front or a seat to slide into can afford it. The accommodation is a reasonable ask if done appropriately and timely. Please reach out to me as I have more to say about the inequalities, mistreatment, and ignorance that persons with disabilities encounter every day.

Jennifer Robb	
First Name	Jennifer
Last Name	Robb
Municipality	Grantwood Village Town
State	Missouri
Comment	<p>Flew Southwest over Memorial Day weekend 2024. They will not give out advance preboard unless you are in a wheelchair or blind. I wear a leg brace and use a cane for anything more than a short distance. I was required to arrive early and beg a customer service clerk where you check your baggage for a preboard pass. Like it isnt bad enough the extra time I need for getting around in the airport plus extra TSA hassles, to beg for a preboard pass and then hope the front row is avail since your leg brace wont let you sit in a normal space. Several airports also make airport wheelchairs inaccessible. They are not at the door - in Denver I had to walk through the entire terminal and then go up a level to find one at my carrier. Not to mention timing my flight to be the time I am off Radicava (liquid ALS med for all the DOT people). The thought of someone throwing out a Rx that costs me \$5900 a month was sickening! Do they make it hard for the disabled to fly because they dont want us to fly? Why must everything we need to fly take twice as long to do? Shouldnt it be the other way around?</p>

Air Travel Stories from People Living with ALS

Cheri Halleran	
First Name	Cheri
Last Name	Halleran
Municipality	White Lake charter township
State	Michigan
Comment	My husband is unable to fly because he can not move out of his wheelchair and transfer to a seat. We would really like to have the ability to fly with him in his wheelchair.

Grace Markee	
First Name	Grace
Last Name	Markee
Municipality	Austin
State	Texas
Comment	When I was 10 years old, my family traveled with my mother who had ALS. My mother at the time was only in year 3 of her total 7 years with ALS. But watching the TSA have to take her out of her wheelchair, mishandle the wheelchair, walk my mother through the narrow scanner without my father, then be searched was very upsetting to my siblings and I. I wish there were someone properly trained to help people with disabilities in the airport.

Carolyn Gray	
First Name	Carolyn
Last Name	Gray
Municipality	East Greenwich township
State	New Jersey
Comment	Trying to figure out a way for my father whom has ALS, to be able to be flown to New Jersey from Florida comfortably since airplanes are not handicapped accessible! Very disheartening!! If he has to go to the bathroom it will be impossible!

Natalie Stewart	
First Name	Natalie
Last Name	Stewart
Municipality	None
State	North Carolina
Comment	Prior to his ALS diagnosis, my dad was traveling unaccompanied from FLA to the Mayo Clinic to determine why he was experiencing

Air Travel Stories from People Living with ALS

mobility issues and weakness. I lived in MN at the time, and met him at the airport. Upon arrival, I could tell he was extremely weak and basically unable to navigate the walk from the farthest point which airport transport could bring him and the first place I was permitted to meet him. When I saw how weak he was, I asked transport if they could wheel him to the chairs by the front door. They said that they had brought him as far as they were permitted, asked him to vacate the chair, and left. Since visiting with him three months previous, he had lost over 40 lbs. and a great deal of stamina and balance. I had no idea how we were going to get to the front door of the airport where there were seats. It was a grueling 30 minute struggle, primarily for him, to make our way to the chairs near the door. Once there, I asked him to sit patiently while I brought the car to the front door. He was having a great deal of breathing difficulty, and was confused about what I was asking him to do. I was unsure if he would be medically safe and walked to the ticketing area to determine if there was anyone who could assist us. The answer was no. I left for the car and returned to the front door, exiting and hurriedly making my way to my dad, knowing that I was not supposed to be parked in front especially with no driver, but I had no other way to get my dad out of the airport and home to rest. It took 15 minutes from the chairs at the front of the airport to my car door, and I was met by the airport authority monitoring the pick up zone. He was as polite as he could be, but navigating his request for my attention and trying to get my dad into the car made our departure from the airport that much longer. Approximately seven months after his arrival in MN, he traveled home to FLA once, and had great difficulty with having his custom chair transported properly. It arrived at the airport when he did, but one of the arm rests had been damaged and the left footrest bent. On the return trip back to MN a week later, his medical bag was accidentally moved and placed in the plane hold. His oxygen and medicine necessary during the flight was not available. It created a great deal of anxiety and discomfort on the flight, and necessitated a trip to the ER once leaving the airport to return his

Air Travel Stories from People Living with ALS

	<p>oxygen levels to a safe place. He had wanted to take one more trip home about two months later, but was afraid that the experience would be unsafe. We repaired the chair without the assistance from the airlines. There was no time to waste in dealing with a claim, possibly having to wait longer than necessary, when my dad's comfort and ability to move about were tied to his custom chair. My dad passed away ten months after his initial diagnosis, and one month after having contemplated his last trip home and deciding it was not worth the risk due to the difficulty in getting help at the airport if needed.</p>
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Eithne Clarke	
First Name	Eithne
Last Name	Clarke
Municipality	None
State	Florida
Comment	The Captain was standing outside the cockpit during boarding and I smelled alcohol. I pretended I forgot something and rushed off to report to the gate agent. He was removed and the flight was delayed for almost 4 hours until the replacement was scheduled.

Bertha Plasencia	
First Name	Bertha
Last Name	Plasencia
Municipality	Sacramento
State	California
Comment	My husbands wish was to go to Disneyland with all his family so we borrowed a scooter from the local ALS & the airlines lost the control knob!! Had to use my perfume bottle top for the whole trip.

Molly Veydovec	
First Name	Molly
Last Name	Veydovec
Municipality	Mcadenville Town
State	North Carolina
Comment	My mom was given less than a year to live. We made it a priority to travel so she could see her family before she was unable to travel. I believe

Air Travel Stories from People Living with ALS

the individual employees did the best with what they were given, but they should be given more to work with. My mom was treated like baggage. She had to wait over half an hour after everyone left the plain for someone to come transport her. Why not give her priority? The person who did move her was rough and pulled at her. She felt pushed and prodded. In a situation where PALS have already lost so much dignity, AIR travel is one place they could be made to feel human.

Dana Lyons	
First Name	Dana
Last Name	Lyons
Municipality	Murfreesboro
State	Tennessee
Comment	Two weeks ago we traveled and were going through Security. My husband has a small electric wheelchair and has a left leg brace to help him stand and walk short distances. At BNA the security folks called a special agent to us and he was training someone. This trainee spent 10 minutes telling us what he was going to do to my husband to check him. They made him stand and he had a full body search where the man grabbed his groin and went up his behind as well as the rest of his body. I had to hold his arm so he wouldn't lose his balance and fall. After other checks, (explosive powder, etc.) they made him continue to stand so they could take his chair to get checked. This process took over 20 minutes and was done in front of everyone at the airport that morning. We were both humiliated. My husband more so after getting felt up. I cried all the way to the gate. This is not the first incident we have had with TSA, just the latest in many. We felt no one gave a crap and if we complained we would have gotten into trouble.

Air Travel Stories from People Living with ALS

Deneen Jenkins	
First Name	Deneen
Last Name	Jenkins
Municipality	Thorntown Town
State	Indiana
Comment	We flew in to Boston. They had someone drop us off at a terminal for an airport bus to the other side of the airport where international is. But they were not handicap accessible even though they said they were. I had to get out of my wheelchair, stand in a rickety metal elevator, then climb giant bus stairs. It was ridiculous. It took so long we almost missed our flight despite having a 2 hour layover. There was also a very long delay getting an airport approved wheelchair and attendant.

Wendy Hatchell	
First Name	Wendy
Last Name	Hatchell
Municipality	Oneida township
State	Pennsylvania
Comment	I do not have a story I do not fly!!!

Hossein Oshrieh	
First Name	Hossein
Last Name	Oshrieh
Municipality	None
State	Kentucky
Comment	I do not travel for the fear of damage to my power wheel chair due to mishandlung and improper storage during flights. The expense and loss of time for required repair is not worth the hassel as well as loss of use during repair.

Diane Layden	
First Name	Diane
Last Name	Layden
Municipality	South Hanover township
State	Pennsylvania
Comment	Approximately three years ago, we flew to San Antonio Texas on Delta Airlines. At that time, my husband was using a foldable power wheelchair , when we arrived in San Antonio, The wheelchair which had been stored

Air Travel Stories from People Living with ALS

somewhere under the plane would no longer work. The power came on, it was fully charged, but would not move. We submitted a claim and they had the wheelchair for the full five days we were in San Antonio, but could not fix the problem. My husband was still able to walk with use of a Rollator which The airline provided for us during our stay, but it certainly was not as useful or comfortable as the power wheelchair wouldve been. Delta did cover the repairs but we had to take the Wheelchair back home to Pennsylvania with us and then mail it out to the company we purchased from who then replaced it. Delta covered all the costs, but it was very inconvenient and stressful for me to have to deal with this. Diane, spouse of person with ALS.

Mr. Paul Miller	
First Name	Paul
Last Name	Miller
Municipality	Scranton
State	Pennsylvania
Comment	I have ALS and we were flying from Newark, NJ to Dominican Republic and we brought my Jazzy instead of my Powerchair. Because the Jazzy is quite a bit lighter 156lbs than my Permobil M300 is over 400lbs. When we arrived at the Dominican airport the Jazzy would not run. It was broken, but we couldn't figure out why. So, we had to have someone push it out to a van and had 2 people lift it into the van. Same thing at the resort only had to get it to the room. I couldn't walk but once in the room I got down on my hands and knees to look at the Jazzy. I noticed that one of the brake handles to lock and unlock the brakes was broken off. They never mentioned that they broke it. We found out later after our week trip that the broken handle was inside the back pouch.

Air Travel Stories from People Living with ALS

Arthur Smallidge	
First Name	Arthur
Last Name	Smallidge
Municipality	Trenton town
State	Maine
Comment	<p>I was diagnosed in January 2023 with Bulbar ALS. I am very fortunate that the disease has been slow in progression. I still have complete use of my limbs and breathing. I can only eat through a feeding tube. I am hesitant to travel by Air because I have to carry my feeding formula which needs to be stored near room temperature. I would not mind paying for extra baggage but I worry very much how this would be stored and transported and possibly lost as these problems are sometimes the rule not the exception.</p> <p>Thanks for accepting my comments.</p> <p>Arthur Smallidge</p>

Christina Buck	
First Name	Christina
Last Name	Buck
Municipality	Seaside
State	Oregon
Comment	<p>We traveled in 2014 when I was still using a walker. We missed our connecting flight (they didn't care) and they broke my walker. I was given a loaner (much too big for me) and after my two week vacation, when I was told I would receive a replacement for the walker they broke, I had no replacement. A replacement came weeks later. I had to use a wheelchair (loaned to us by the hotel) during our vacation.</p> <p>The last time I flew (with my wheelchair, which was put in the cargo in a wheelchair travel bag I purchased for hundreds of dollars) was the last time I will ever fly. My disability has progressed and there is no way I could fly because I would not be able to use the bathroom and there is no doubt my wheelchair would be damaged by the airline and they would do nothing about it if it were. Reading about how a woman died after her customized wheelchair was damaged and the airline</p>

Air Travel Stories from People Living with ALS

	<p>refused to replace it is horrifying.</p> <p>I am sick and tired of feeling like the entire world would prefer I simply die than be accommodated in any way! THE ADA LEGISLATION IS OVER THIRTY YEARS OLD IN THE UNITED STATES!!!!</p>
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Andrew Weyker	
First Name	Andrew
Last Name	Weyker
Municipality	Appleton
State	Wisconsin
Comment	<p>I have not had any air travel because I dont have any idea how they can accommodate me. I cannot transfer. I need to be hoiered in/out of my seat.</p> <p>No way I can use a bathroom on a plane. Even an airport bathroom is useless unless I bring a hoyer.</p> <p style="text-align: right;">So how can I even think about air travel?</p>

Mr. Michael Lynch	
First Name	Michael
Last Name	Lynch
Municipality	Manhattan borough
State	New York
Comment	<p>Traveling with a power wheelchair watched handlers try and lift it from the movable foot rests and they broke one and jammed the seat raise mechanism so it couldnt be used. Took 4 attempts and almost 3 months to get it fixed. Baggage handlers are not trained to deal with power chairs</p>

Stephen Parker	
First Name	Stephen
Last Name	Parker
Municipality	None
State	Louisiana
Comment	<p>Several years ago, I accompanied my dear friend - who was surviving and disabled - to ALS Advocacy Day at the Capitol. On the way home at Regan National, TSA demanded a scan of my dear friend - who was in a wheelchair - to</p>

Air Travel Stories from People Living with ALS

	<p>get out of the chair (she couldn't). So the TSA agents PHYSICALLY LIFTED her to pass the wand. Meanwhile, perfectly-abled people passed by. The entire situation was humiliating. Not only for my dear friend, but for the TSA agents. It makes no sense. This has to change.</p>
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Cathy Kettner	
First Name	Cathy
Last Name	Kettner
Municipality	Greenville town
State	Wisconsin
Comment	<p>I have ALS. I do not currently have a story to tell you, but will soon be in a wheelchair. I also have upcoming research that will require me to travel from the Midwest to the East Coast. I would certainly like to know that that travel will go smoothly. I have heard many stories about the mishandling of motorized wheelchairs. Please continue to do all you can to help us in this area. I would like to know that with travel that both should I and my assistive equipment will make it in one piece.</p>

Roy Mammen	
First Name	Roy
Last Name	Mammen
Municipality	Fulshear-Simonton CCD
State	Texas
Comment	<p>I am an ALS patient on a Permobil M3 Power wheelchair for the last 5 years from 2019. This is a specially customized wheelchair with my specific measurements and needs. Additionally, 24 hours a day, I am on a Trilogy AVAP Breathing machine (portable), that's attached to my wheelchair. This specially customized wheelchair allows me to constantly tilt, incline and change the position for ease of breathing, and comfort; along with allow me to move the legs and back for needed body movements to avoid skin breakage (I am Diabetic also).</p> <p style="margin-top: 20px;">Due to my ALS disability, I am unable to breathe by myself, walk, stand or even move any of my limbs; and completely dependent on my wheelchair and the AVAP all the time</p>

Air Travel Stories from People Living with ALS

continuously.

My favorite hobby been traveling but avoiding it altogether due to the horror stories about wheelchairs getting damaged during air travel. Additionally, this situation takes my opportunity to travel to participate in medical trials & treatments and attend various family events which are all very important for me.

I am hoping the Government & Airline authorities would do the required changes and make progress soon.

NOTE: Average life span of an ALS patient is 2 to 5 years.

R Castillo	
First Name	R
Last Name	Castillo
Municipality	Newton
State	Massachusetts
Comment	<p>First off, before my diagnosis, I was a seasoned traveler who flew domestically and internationally. I have also traveled with my mom (who uses a wheelchair) in Asia. Two years ago my husband and I traveled to CA from Boston with a stopover at Dallas (DFW) via American Airlines. It was our first time flying since my diagnosis (and the start of the pandemic). At the time I only had a manual wheelchair so it was hard enough because my husband had to pull our carry-ons while pushing me. At DFW, no wheelchair handler met us at the gate so they had to ask a supervisor who took us on those airport golf carts. He flagged down a handler and said the handler would take care of us. As expected, since DFW is a big airport, we had to take the airport train to another terminal building. Once we got there, I told him since we had time and since there was a cafe near our gate, I requested that he take us to the cafe. I then asked if he would be back when it was time to board and he said "oh no, I technically work in another terminal and only brought you to this building because the supervisor flagged me". Bottom line, he left us. Thankfully my husband</p>

Air Travel Stories from People Living with ALS

	<p>was with me but if I was traveling alone, it would've been difficult, if not impossible, to pull the carry-on, push the wheelchair, go the restroom, etc. After the trip, I called to complain to AA and they gave me and my husband credits for a future flight and acknowledged that the ground staff at DFW needed training since they had been getting a number of ADA complaints. I also got myself a power wheelchair so that I could be more independent. I guess I assumed that wheelchair assistance meant that the handler stays connected with you until you board the plane. The handler doesn't have to be with you 100% until boarding but I expected him to come back 30-40 mins prior to see if I needed anything prior to boarding (which is how it is in Asia). Needless to say, it was a horrible first experience traveling as a disabled person.</p>
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Elsa Churchill	
First Name	Elsa
Last Name	Churchill
Municipality	San Francisco
State	California
Comment	Traveling with a person suffering from ALS is so burdensome on top of an already devastating disease. Please help us fix the challenging travel logistics of wheelchair accessibility. It is so challenging it makes the thought of travel almost not worth the effort.

James Kagoshima	
First Name	James
Last Name	Kagoshima
Municipality	Fairfield
State	California
Comment	To whom may be reading this letter. I understand the importance of security in our country, but while people are entering this country with almost Unfettered access and travel, my wife Kelly and I after visiting our kids and grandchildren, were traveling from Nashville back home to CA. At the time Kelly was in a wheelchair barley able to walk on her own anymore, she had a clearly visible Trach a feeding tube and could no longer speak. Yet

Air Travel Stories from People Living with ALS

because we were traveling with bags of formula, which was her only source of nutrition, security said it was necessary to all but strip search her publicly. That was so humiliating for both of us, but especially Kelly!! I'll try not to use this platform for my personal bash on current travel policy, but the heightened TSA security could be and should be used elsewhere!! I think we all truly know that. In light of that I feel their should be policy put in place that allows confirmed ALS patients less hassle when traveling, they are already struggling to live! Kelly has since passed after a grueling 8 year battle with ALS which takes every bit of dignity from you only to trampled on by our own government! I urge you to please work on this, if this was your wife you would feel the same frustration I do. Sorry for the rant. Sincerely James Kagoshima.

Gerri Lynn Lynn Zschetzsche

First Name

Gerri Lynn

Last Name

Zschetzsche

Municipality

None

State

Missouri

Comment

My husband, Peter, has ALS. We have always traveled and want to continue to do so as his symptoms get worse. However, it becomes harder all the time. TSA is not well trained on handicapped/wheelchair accessibility. It takes so much more time as they search him so much. There shuld be a scan that a wheelchair can fit through. We also travel with medications and is very inconsistent depending on what city you are in. Our bag is always pulled and usually for different reasons. We understand the necessity of this but you can't plan when there are no specific rules or things each TSA agent is looking for.

I would think most airlines would provide a seat as close to the front as possible but that never happens either, so he has to walk past everyone seated hanging on to the seats. Some airlines let us board first but not all of them.

Air Travel Stories from People Living with ALS

Ms. Mary Lynn Lynn Larson	
First Name	Mary Lynn
Last Name	Larson
Municipality	Winneconne Village
State	Wisconsin
Comment	<p>It's difficult traveling because one few airports actually follow through on their commitment to provide you with transportation to your gate. Two once you're at your gate there are significant delays in getting you to the plane because the staffing issues. Three getting on the plane in a wheelchair is difficult and staff isn't willing to assist you as you're trying to get on board and then you're crammed into an area with your medical equipment and not assisted. It's your dependence upon other travelers to assist in getting your luggage into the proper location. Being challenged with physical deterioration doesn't allow you to get your luggage overhead like the rest of the passengers too. Staff can be incredibly rude and the delays in trying to locate someone to assist you. And then once you've landed you have to go through the same type of situation in asking someone for assistance to get your luggage down. Coordinating that ride off the plane into your pickup area and all done with mumbling under the breath and then the expectation that on top of everything else you've had to do you have to tip people in multiple scenarios. we shouldn't have to pay to have service provided to us.</p>

Ms. Miriam Brodkin	
First Name	Miriam
Last Name	Brodkin
Municipality	Thousand Oaks
State	California
Comment	<p>It is an absolute nightmare traveling when you are disabled especially with a wheelchair. Ground crew and flight attendants need to have more patience and passion for those who can't simply walk through the airport or getting on the plane. More accommodations for the disabled especially those with ALS need to be made so they can have a good experience just like all the other passengers.</p>

Air Travel Stories from People Living with ALS

Laura Campbell	
First Name	Laura
Last Name	Campbell
Municipality	None
State	Virginia
Comment	Wheelchairs are vital to a person with ALS because it's sometimes the only area of control they have left. When ALS takes a person's ability to run, walk or even stand, their wheelchair becomes a part of them. Being without their chair if damaged during travel can be painful, frustrating and hopeless. My dad was often described "like a rock" due his tall stature and physique. Having a specialized chair was his last connection to any physical control he had left. We did not have any air travel difficulties but had we been, it would have been an utter nightmare trying to secure a replacement chair to provide the level of comfort a person with deteriorating body tissue needs.

Carlos Mateus	
First Name	Carlos
Last Name	Mateus
Municipality	Walnut Creek
State	California
Comment	I usually have trouble with battery. Employees are not always trained on allowed capacity and there is a typical struggle when you show the battery, even though it clearly shows all information in a sticker. One airline placed a warning sticker (with bad quality) around the battery that damaged the original sticker when removed... - no stickers on battery!

Mr. Paul Klotz	
First Name	Paul
Last Name	Klotz
Municipality	Mobile
State	Alabama
Comment	On a trip to Italy with the Mobile Chamber of Commerce on the return flight Delta tore up my rolling transport wheel chair. While they replaced it it took a month to do so.

Air Travel Stories from People Living with ALS

John Latham	
First Name	John
Last Name	Latham
Municipality	St. Louis
State	Missouri
Comment	<p>I'm concerned about the story I've heard from a friend who recently traveled to st Louis from DC. She was telling the grounds crew to please not life her 500lb \$75000 power chair as it had already been damaged in the past and she was afraid it would happen again. Unfortunately, her plea was not heard and the chair was lifted which ultimately led to her control console and steering apparatus being damaged. This is unacceptable. The process for which she was then forced to go through by sitting at baggage claim for recovery/damaged bags was hard to hear. The way the claims process works requires that the claim be made before leaving the airport. Having to do this causes delays to trips and causes incredible pain and anguish to the affected person. Please remediate this issue by training our grounds crew and putting in place a proper storage area for power chairs to ensure safe transfer of medical equipment through our flight partners.</p>

Martha Tofteland	
First Name	Martha
Last Name	Tofteland
Municipality	Orono
State	Minnesota
Comment	<p>I'd say my worst nightmare came when we traveled to Washington, D.C. for the first time to participate in this enormous annual ALS Advocacy Conference. My husband's mobility had changed to the point that he needed the assistance of a walker to get around safely by foot, and could use a mobility scooter for more intensive travel needs. But the walker was key at this stage of the disease. When we arrived in D.C. we were delivered a broken walker -- one of the brakes had completely snapped off. Here we were in a new city as tourists with no connections for a quick fix. Meanwhile we were looking forward to staying with family in town whose home was "accessible enough" for our needs, however, we had expected Ryan would</p>

Air Travel Stories from People Living with ALS

	<p>have a sturdy walker to rely on. Damage to mobility equipment is an actual danger for the people that need these tools. It's not just a "nice to have," these pieces of equipment are essential for the safety of people who can no longer walk on their own. ALS is a disease that robs a person of all function. Please do better to give them some dignity when they travel. It truly may be their last trip by plane. And that's not dramatic, that's the truth. Average life expectancy is 2-5 years from diagnosis so to get on a plane requires a lot of work.</p>
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Joanne Somerday	
First Name	Joanne
Last Name	Somerday
Municipality	River Bend Town
State	North Carolina
Comment	<p>My son and his family and I took my husband with ALS to visit Argentina for a month where my son was living because of a job related assignment. People were wonderful assisting with his transportation. A narrow wheelchair carried him down the aisle to his seat. He was using a battery powered wheelchair that had a battery with a gel. It took a couple of hours communicating with the manufacturers of the wheelchair to send a written letter stating that the battery did not contain acid. We were told to not let the airline personnel remove the battery because of the difficulty reinstalling it. The paperwork came through and the wheelchair survived the trip. I carried the computer which operated the wheelchair with me. At the time there were not family bathrooms so using the bathroom was an issue having a choice of either men or women. All in all, considering the magnitude of transporting someone who was not able to move very well nor communicate it was a very positive experience.</p> <p>The lack of handicap accessibilities in Argentina was met by the kindness of the people who at one point people on the street lifted the wheelchair with my husband in it to the sidewalk. He let the children ride in the chair as this was the first time in this village that they had seen one.</p>

Air Travel Stories from People Living with ALS

Nancy Dallas	
First Name	Nancy
Last Name	Dallas
Municipality	Orange
State	Texas
Comment	We flew several times and each time, the staff just wasn't familiar with a power chair and how to tag it for flight (weight, battery, how to work one in order to get it under plane, etc) We flew to Vancouver, Canada and all went well. (I had printed a booklet of information for staff to know how to maneuver chair) on our flight back, we were told they couldn't fly anything over 250 lbs (chair is 400 lbs). It was the same airline to and from, so just irritating to get back on the plane!

Angela Wonitowy	
First Name	Angela
Last Name	Wonitowy
Municipality	None
State	None
Comment	Traveling from Abbotsford to Edmonton tomorrow - so far there have been 3 phone calls and 2 emails regarding being able to bring my travel buggy wheelchair. They are now saying I have to carry the battery and although it is only 24v there are 2 - the airline only allows one. This is my legs and this is how the wheelchair is made AND everything online says it is acceptable for flying but the airline says no then they say yes then they say no - depends who you talk to! We shall see when we get there tomorrow!

Mr John Roselle	
First Name	John
Last Name	Roselle
Municipality	Fishers Town
State	Indiana
Comment	My wife was diagnosed with ALS in 2021. We got her power chair in May 2022 and she took her first trip to Philadelphia in June 2022. The chair was significantly mishandled and damaged on both legs of the trip, requiring an

Air Travel Stories from People Living with ALS

immediate replacement, which was unavailable. I took photos of the grounds crew. actually loading the chair onto the ramp to go up into the plane. They placed a 400 pound. on its side, destroying one of the arms and the communication links. It was obvious they had no idea how to handle the chair or how to get it into the plane. As a result of that experience, we have not tried to fly again with that chair, and instead have been subjected to very long drives in our mobility van.

John Bach	
First Name	John
Last Name	Bach
Municipality	Destin
State	Florida
Comment	I must say my experience have positive With airline. Bathroom need a lot of work To accommodate people who are disabled Not safe for travels in a wheelchair No safe equipment at all. People were very kind and helpful God bless

Kate Vasiloff	
First Name	Kate
Last Name	Vasiloff
Municipality	None
State	Virginia
Comment	My dad's dream was to go to Greece where his father was born. Once his diagnosis hit, it wasn't long before he was in a motorized wheelchair. He wanted nothing more than to make the trip to see his homeland, but his anxiety and fear over possible damage or loss of his wheelchair was paralyzing. He ultimately decided he could not risk such a trip and left this world without accomplishing this life-long dream. This legislation would help people like my dad who want to continue living their lives with ALS more realistic, peaceful, and enjoyable .

Air Travel Stories from People Living with ALS

Hearl Clay	
First Name	Hearl
Last Name	Clay
Municipality	Shoreline
State	Washington
Comment	Have had employees show up that cannot transfer me. Have been twisted to a point it pulled my back. Set in the armrest so had a sore tailbone for flight. Ive had good people as well. Last trip was a nightmare

Ms. Trisha Guggenmos	
First Name	Trisha
Last Name	Guggenmos
Municipality	West Des Moines
State	Iowa
Comment	Traveling for my sisters wedding. My sister almost didnt pick where she wanted to get married because she knew we would have to travel with my mom with ALS. We were so scared they would break her wheel chair, which is our livelihood that we drove her wheelchair 1200 miles to ensure it got there safe and we had a vehicle there to accommodate a power chair. Flying with mom, trying not to make her feel like a burden they at first would seat us together and someone needed to help, they also didnt realize that once seated she needed help back into the chair. Need a way to feel comfortable for people to get their power chairs where they are flying to not have to worry about if the chair will make as with ALS they have enough to worry about

Ashok Parikh	
First Name	Ashok
Last Name	Parikh
Municipality	None
State	Florida
Comment	Last January I Travelled from Miami to India and back for 31 days period It was very comfortable beside some hurdles with security in regards to my nutrition supply And some DME but upon explaining my ALS condition the staff at every point helped us and even wheelchair people take care of us with all

Air Travel Stories from People Living with ALS

	<p>arrival departure point. It was pleasant I saw all my family members back home. I am glad I visited them last year as now my disease has progressed a lot and very difficult to travel Thanks everyone for their support</p>
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Tadesse Hassen	
First Name	Tadesse
Last Name	Hassen
Municipality	Apple Valley
State	Minnesota
Comment	<p>Lost wheelchair at Washington Dulles airport (IAD). We have to wait for more than two hours to get it. We missed the connecting flight. The next flight was 7 hours away. it was very long day.</p>

Mrs. Wilhelmina Burckle	
First Name	Wilhelmina
Last Name	Burckle
Municipality	Irvine
State	California
Comment	<p>My husband Jim passed away from ALS on July 6, 2016. In the three years after diagnosis in 2013, we tried to fulfill many of his wishes, which included travel.</p> <p>His mobility scooter (which he used until he needed to be in a power wheelchair) was damaged on an Alaska Airlines flight from being roughly handled by a baggage handler on the flight between Seattle and Vancouver. It caused a stress fracture at the base of the steering unit, which caused the steering unit to break off during our trip (we were on an Alaskan cruise).</p> <p>Alaska Airlines took full responsibility and replaced the scooter. I conveyed the story of the interaction with the baggage handler on the tarmac (where we had to board the plane), who was very rude, and said the baggage hold was already full, and how was she supposed to still fit the scooter in the plane. (Alaska Airlines had been notified prior to our trip that my husband would be in a mobility scooter). The Alaska Airlines rep I spoke with was appalled</p>

Air Travel Stories from People Living with ALS

at this, and very apologetic.

The other difficulty that my husband faced was going through Security. On several occasions, the TSA agents would ask my husband to get out of his mobility scooter to walk through the scanner. So I would have to tell them, he CAN'T walk through the scanner, he has to stay seated in his scooter because he has ALS! It was humiliating for my husband.

I hope that Jim's experiences (and as his caregiver, mine as well) will be useful to the DOT with the proposed changes to the Air Carrier Access Act rules.

Sincerely,
 Wilhelmina Burckle
 Jim Burckle's wife and caregiver

Ms. Kelly Stonebock	
First Name	Kelly
Last Name	Stonebock
Municipality	Peoria
State	Illinois
Comment	My dad had ALS and was flying to Florida. We shared with the airlines that he had ALS and needed help getting on/off the plane. He wasn't heavily using a wheelchair yet but was on the brink of needing it. The airline (Allegiant) was not at all supportive because he didn't look like someone with a disability. They denied him preboard and didn't assist him on the flight when requested. It was a really upsetting experience and he never flew again. So if you could please push for education around ALS that even if the person looks ok, that they may be having invisible disabilities/pain/discomfort.

Scott Toland	
First Name	Scott
Last Name	Toland
Municipality	None
State	Colorado
Comment	About 5 years ago, my late wife, who had and died from ALS, courageously risked her health

Air Travel Stories from People Living with ALS

and the quality and length of her life to participate in an ALS clinical trial at Stanford University.

She did this, so that hopefully there could be a cure found for ALS and that no one would have to live with and die from this terrible and devastating disease. During that time, my wife could not speak well (unintelligible) and needed assistance with walking and barely being able to walk.

We traveled back and forth many times from/to the Denver International Airport (DIA) and the San Jose Airport. As her caregiver, I did most of the planning, coordination, and literally, the heavy lifting. There were times when I was carrying on and down the plane aisle 5, 6 or 7 items, including several pieces of heavy medical equipment to help with her medical support for breathing, saliva, etc., which was very difficult to do.

All the carry-ons, including our medical equipment went through the x-ray screening. One time, at DIA, before her suction machine went through the x-ray machine, it had accidentally turned on while laying on the conveyor belt. It's battery powered.

The TSA agent kind of backed away from the suction machine. He saw moisture moving in it and said to me, "There's a lot of liquid in there, what is it!?" I shut it off and looked at him like "really?" in disbelief in that he had never come across a suction machine before and also knowing that I had emptied it before our trip to the airport and that there shouldn't have been that much liquid in it. I told him it's a suction machine and that the liquid in it was saliva, of course!

He wanted to see inside it.

So I opened it's travel case, opened the cup that holds the saliva, and then showed him the tablespoon of my wife's saliva in it. He said, "oh, okay". From then on, I tried to make sure the suction machine was totally empty of any saliva before we got in the security lines.

Air Travel Stories from People Living with ALS

Even without having to address TSA questions or actions like this, it was always very difficult getting myself, our carry-ons, the medical equipment, and my wife through security. My wife would be in TSA's control, unable to fend and/or speak for herself, if necessary. I would always tell the TSA that she had ALS and what she was or was not able to do.

All this, while trying to keep track of our personal belongings like my wallet, cellphones, keys, shoes, purse, all our carry-ons, the medical equipment, and my wife. I tried to stay close to her or keep a close eye on her, as sometimes TSA would screen her separately away from me and the security line, while I was also surrounded by many other people going through security. It was like juggling 8 balls at once and was very stressful!

There was a time in the San Jose Airport that we couldn't find a "family style" restroom, so that I could help my wife go to the bathroom. My wife could barely walk. So the only choice we had was for her to go into a regular women's restroom and hope she would make it in and out without falling. Thank goodness she received help from other women in the restrooms or they'd come out and tell me how she was doing or that she was okay!

Afterwards, we contacted the San Jose Airport about this issue and found that their website had incorrectly listed all of their "all gender" restrooms in Terminal B and none in Terminal A, where we had been. They acknowledged the mistake and stated that it would be corrected on their website.

We would travel with our wheelchair and/or walker. Our walker was damaged when it was checked in for one of our flights, a handle bar height adjustment tightening knob broke off. We were still able to use the walker by tightening the handle bar with pliers. I recently replaced the knob for my mother.

Another issue that would arise is the tipping of airport or airport contracted personnel for

Air Travel Stories from People Living with ALS

wheelchair assistance. Whether to tip them or not, in consideration of the clinical study expenditure reimbursement rules, which generally didn't allow for tips. The no tip rule was ridiculous.

Some wheelchair personnel would not accept tips and some would want a tip and would complain that my tip was not enough. It became confrontational with one of our wheelchair helpers at DIA because he didn't think our \$5 tip was enough. Later on, I contacted the DIA Administration and third party contractor, who simply said tips are accepted.

In summary, the most challenging parts of traveling were getting from the airport's entrances to our seats in the airplanes, especially check-in, security/TSA, and down the narrow aisles of the airplanes, with so many carry-on items, while trying to keep an eye on and help my disabled wife with every part of this.

Just about every part of the airport/airplane experience was difficult, and I've highlighted some of the most significant incidents here. It's probably something someone would have to experience themselves to truly understand how challenging it was and can be.

Thank you for your consideration of my comments. While many of these issues may not address exactly what you are trying to fix, all these issues deserve your consideration and review for improvement.

I hope there have been and will continue to be changes made that will make it easier for people with ALS and their caregivers to fly.

If you need any additional clarifying information and/or questions, please contact me.

Scott Toland
ALS Caregiver
smt200@msn.com
Franktown, CO

Air Travel Stories from People Living with ALS

Mr Nathan P. P. Thomas Sr.	
First Name	Nathan P.
Last Name	Thomas
Municipality	None
State	Maryland
Comment	I am an Advocate for ALS, not a patient.

Ms. Sarah Felts	
First Name	Sarah
Last Name	Felts
Municipality	St. Louis
State	Missouri
Comment	People with ALS, like all people who use mobility aids, must have their wheelchairs and other assistive devices protected throughout air travel. And if damage does happen, repairs and/or replacements must happen immediately.

Sarah Pierson	
First Name	Sarah
Last Name	Pierson
Municipality	Montgomery township
State	Pennsylvania
Comment	In 2019, American Airlines overbooked a flight from Philadelphia to Orlando that my parents, my friend, and I were booked on. We had paid hefty additional fees to be able to choose seats close to the front and the bathroom, and with additional room - all features my father, one year into his ALS battle, needed to be able to fly safely and comfortably. We found out at the airport the morning of our flight that all four of our tickets had been cancelled due to their overbooking. We were devastated, as we were headed to Florida to join other family already there, for what we knew would be Dad's last vacation. We didn't understand why they chose to cancel the tickets of passengers who had paid several extra fees - it seems more logical, and fair, to do so to those who did not (though, overall, the concept of overbooking flights and canceling anyone's ticket is inherently unfair to customers). The customer service at the ground floor ticket desk was non-existent -

Air Travel Stories from People Living with ALS

	<p>even hostile - as they looked at my father, unable to walk without his rollator - and did nothing for us; they were rude and dismissive. The staffer at the gate desk was not much better, but they did, after much time waiting, finally let us know we could board - but our seats were now in the very last row of a very large aircraft. We explained this would be incredibly difficult for my disabled father (and us, to support him) - but we were not accommodated. My father was a trooper - always - but overall this flight experience was unnecessarily stressful, at times embarrassing, discouraging, and definitely put a damper on the trip. We all felt less-than, thanks to American's policies and "service."</p>
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Ann Michelle Collins	
First Name	Ann Michelle
Last Name	Collins
Municipality	None
State	Washington
Comment	<p>My husband has ALS and is wheelchair bound. He needs a lift to transfer to another chair or bed. There are no airlines that can accommodate his wheelchair. We need the airlines to install a floor locking mechanism that can lock in a wheelchair. We miss traveling by plane. We use to fly quite frequently. My husband would love to be able to see family and friends that live across the country. This does affect his quality of life.</p> <p>Sincerely, Michelle Collins</p>

John Mark Wallach	
First Name	John Mark
Last Name	Wallach
Municipality	Blue Ridge district
State	Virginia
Comment	<p>I travel quarterly to see a doctor, in addition to personal travel, which my wife and I are doing while I am still capable. The issues I normally face fall into a couple of categories. In category one, I find myself often training the staff on how to document my chair for travel. Category two is that I wait a very long time for a gate-</p>

Air Travel Stories from People Living with ALS

	<p>checked chair to be brought up so that I can get off the plane. In category three, there have been times when they will not bring the gate-checked chair to the plane, and I've actually had to walk up the gateway to get it. Up until now, I've used a folding electric travel chair. However, I am going to a chair that will no longer fold. I'm very concerned about it being damaged as it is an expensive chair and becoming my sole mode of ambulatory transportation.</p>
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Ms. Melissa Henderson	
First Name	Melissa
Last Name	Henderson
Municipality	West Bradford township
State	Pennsylvania
Comment	<ol style="list-style-type: none"> 1. My wheelchair stability wheels were bent in storage and I didn't notice until we got home. Claims can only be filed at the airport before leaving. We repaired at our own cost. 2. I've been repeatedly denied pre-boarding even when noted on the boarding pass. 3. I've been refused wheelchair assistance at the arrival airport even though I had it at the departing airport due to miscommunication. The pilot had to call for a chair and it took so long our bags were being picked up as unclaimed luggage! 4. TSA agents, even with pre-check, push companions through and leave me abandoned, then don't understand why I need hand screening. Before pre-check I waited 45 minutes at MCO in the handicap line before an agent finally screened me, and only because a wheelchair attendant behind me demanded they do it. My family was trapped on the other side!

Mr. Donald Willames	
First Name	Donald
Last Name	Willames
Municipality	None
State	Florida
Comment	<p>Air travel has not been a good experience for us since my husband started using his wheelchair. Our first trip from Florida to Philadelphia, the</p>

Air Travel Stories from People Living with ALS

foot rests were lost and had to be replaced which we never received until we returned from our trip. We had to rent a wheelchair while we were on our vacation.

The second trip the wheelchair was heavily damaged and had to be replaced which took a few weeks.

The third trip we had a layover returning from Vancouver to Florida. When we landed in Dallas, the wheelchair could not be located which caused issues with using restroom facilities before the 2nd leg. We were told the wheelchair had already be loaded on the flight to Florida. Once we landed in Florida, the wheelchair could not be found. We spent over an hour while they tried to find it with no luck. We were told they would notify us later when they found it but we couldn't drive home without a wheelchair. We were told that someone would get us to our car but that we couldn't take the "airport" wheelchair home. After much arguing we finally got them to borrow their chair until ours was found. It was a nightmare to say the least.

All of the chairs I am speaking about were manual wheelchairs because quite honestly I do not trust the airlines with our very expensive motorized chair. In all of these incidents I felt that airline personnel had no clue the ramifications of their actions or understanding of what a handicap person needs. There needs to be much more training.

Margarita Flener	
First Name	Margarita
Last Name	Flener
Municipality	Sinton
State	Texas
Comment	I don't fly. Scared

Mrs. Ann Scott Trapp	
First Name	Ann Scott
Last Name	Trapp
Municipality	Mason
State	Ohio
Comment	Had first row seats in first class. Had to take a small portable lift seat on the plane. Flight

Air Travel Stories from People Living with ALS

attendants did t know what it was and they were going to make my son and I remove it. I wouldnt be able to lift my son up without the lift seat. They finally allowed the portable lift seat. Its a spring up seat when the patient gets up with help its easier for the patient and the caretaker. I just think it would be easier if flight attendants understand what the portable lift seat is for and what they look like.

Had a horrible experience going through the gates with my son in a wheelchair. The guy that was checking travelers insisted my son take his shoes off and he was paralyzed. He couldnt reach down to untie his shoes and I said Im his mother Ill assist him. They basically yelled at me and said I wasnt aloud. it was traumatic for my son & me. I even explained he was partially paralyzed and needed assistance. Anyone could see he was paralyzed.

Dina Cellini	
First Name	Dina
Last Name	Cellini
Municipality	Bal Harbour Village
State	Florida
Comment	Lost wheelchair on flight. There sometimes is a disconnect when you get out of wheelchair at the top of the jetway before entering the plane. They put it underneath with the baggage and gets lost.

Richard Keeling	
First Name	Richard
Last Name	Keeling
Municipality	Denton
State	Texas
Comment	I dint have a story to share because it has been absolutely impossible for us to travel by air. We used to travel to Europe and had so many trips planned while Richard could still enjoy the travels and we simply cannot find an airline e to accomodate Richard and his chair! We are so frustrated with the airline industry!

Air Travel Stories from People Living with ALS

Mrs Patricia Galvin Galvin Bloom	
First Name	Patricia
Last Name	Galvin Bloom
Municipality	Pawling Village
State	New York
Comment	This is very important. We have heard about travel nightmares. Fortunately, we have had positive experiences Jet Blue and American Airlines.

Adnan Mujic	
First Name	Adnan
Last Name	Mujic
Municipality	Largo
State	Florida
Comment	Theres needs to be better accommodations for people living with ALS when it comes to travel especially the long lines at airports.

Don King	
First Name	Don
Last Name	King
Municipality	Asheville
State	North Carolina
Comment	I cant speak well,I have a card, they. Seldom read it. I cant raise my hands

Ms. Karie Mitchell	
First Name	Karie
Last Name	Mitchell
Municipality	Homewood
State	Alabama
Comment	Appreciate the very SWIFT help received in airport to shuttle bus and next gate at Philly. I was assured you WILL make your flight and A wheelchair will be waiting when your shuttle arrives at the next location. Please ensure personnel in ALL AIRPORTS are trained in this area and to be very reassuring as traveling as a handicapped person can be very stressful. Thank you!!

Air Travel Stories from People Living with ALS

Mrs. Jill Spencer	
First Name	Jill
Last Name	Spencer
Municipality	Rocky River
State	Ohio
Comment	<p>My husband was using a scooter and we were flying internationally to Ireland from Cleveland making a connection through O'Hare. His scooter was put in the luggage hold during the flight and we were told it would be delivered to our arrival gate in Chicago. We waited for over 30 minutes for it and then went to the next departure gate to see if it was delivered there. It took us over an hour to track the scooter down and almost missed our connecting flight to Ireland.</p> <p>We also flew first class to visit family in Florida and my husband was using a bipap machine. The flight attendants were unfamiliar with the equipment and at one point we thought we were going to be asked to deplane because of the bipap. Flight attendants need to be educated on this medical equipment.</p>

Maria Miller	
First Name	Maria
Last Name	Miller
Municipality	None
State	Texas
Comment	<p>Yes in Ft. Lauderdale airport, the assistance for the handicapped person was not helpful at all and lost his luggage that we never got replaced.</p>

Ireland Bender	
First Name	Ireland
Last Name	Bender
Municipality	Concord township
State	Ohio
Comment	<p>I am writing on behalf of my dad, Stan Bender. He was diagnosed with ALS in 2016. We have traveled with him from Ohio to LA, to New York, Atlanta, Bahamas, etc. We have never had a good experience flying with his chair.</p> <p>Has your wheelchair ever been lost or</p>

Air Travel Stories from People Living with ALS

damaged while traveling? -- Yes. Almost every time he flies with his wheelchair, it comes back broken or messed up. It takes months for a repair representative from the company to come fix it.

Have you experienced challenges getting your device repaired? -- It takes months to repair my dad's wheelchair.

Have you ever been in a situation where airline employees needed additional training for assisting a person living with ALS or their battery-powered assistive devices? -- On one flight, my dad was physically dropped while he was moving moved from the aisle chair to his wheelchair on the connecting bridge.

John Koten	
First Name	John
Last Name	Koten
Municipality	Sacramento
State	California
Comment	<p>As I sat in my seat on the plane, my heart pounded with a mixture of excitement and trepidation. I was heading to Tampa Bay for the first time, eager to experience a change of scenery and soak in the warm Florida sun. But as someone living with ALS, every journey came with its own set of challenges.</p> <p>As the plane taxied to the gate upon landing, I mentally prepared myself for the usual routine: waiting for assistance to disembark, navigating the airport in my wheelchair, and finally, setting off to explore the city. But as I was wheeled off the plane, a sinking feeling crept into my chest.</p> <p>My wheelchair was nowhere to be seen.</p> <p>Panic washed over me as I realized I was stranded, alone and vulnerable, in a city I had never been to before. The airport staff assured me they were looking into the situation, but minutes turned into hours with no sign of my wheelchair.</p>

Air Travel Stories from People Living with ALS

My anxiety soared as I imagined all the scenarios playing out in my mind. What if my wheelchair was irreparably damaged? What if it was lost altogether? How would I navigate the unfamiliar streets of Tampa Bay without it?

As the hours dragged on, my frustration turned to despair. Tears welled up in my eyes as I felt the crushing weight of my disability, the sense of helplessness consuming me. I felt isolated and abandoned, far from the comfort and familiarity of home.

Eventually, a replacement wheelchair was located, but the damage had been done. The experience had left its mark on me, a reminder of the constant challenges I faced as someone living with ALS. And as I rolled through the streets of Tampa Bay, the city that had once seemed so full of promise now felt like a lonely, unwelcoming place.

Shalyn Carpenter	
First Name	Shalyn
Last Name	Carpenter
Municipality	None
State	Oklahoma
Comment	Transport chairs at most airports are very uncomfortable since a person with ALS needs to sit in them sometimes for hours before loading plane. Transport chairs need to be housed outside where ALS patients are dropped off. Airport staff dont understand how costly ALS equipment is or how to handle them. My rollator just simple folds and the brakes were bent and the brake system was messed up. They need a special way to store equipment that is checked in. Just because it folds is not a reason to throw it around. Baggage claim- an airport assistant needs to bring your ALS equipment to you and not put it on the belt to roll around.

Air Travel Stories from People Living with ALS

Melissa Kemmerly	
First Name	Melissa
Last Name	Kemmerly
Municipality	North Little Rock
State	Arkansas
Comment	Please support this change! People living with ALS and their families deserve to be able to travel easily.

T Luth	
First Name	T
Last Name	Luth
Municipality	Amarillo
State	Texas
Comment	<p>I fly fairly regularly. I bought a wheelchair and a wheeled walker and they have flown with me numerous times. Every time they flew, something was either damaged or lost. My seat cushion was lost, wheels had chunks taken out of them, wheels came off the walker and had to be replaced. Once, my walker was folded in a way it wasn't meant to be folded. When my wheels are damaged, I'm unable to leave the airport on my own as I cannot walk with one of these devices. Luckily, my husband was able to use an airport wheelchair to help me.</p> <p>Another time, our international flight arrived late. Our luggage, and my movement helpers were on another flight. We were to stay at a hotel overnight. The airport had no backup plan to help me get around without my devices. My husband put me on a luggage carrier to help me get to the shuttle. Once inside the hotel, he used another luggage carrier to help me to the room. Thankfully, once inside the room, I was able to hold onto the walls to go from bed to the bathroom. Hotels should have a wheelchair available. Airports should have backup plans and airplane stewards should be taught how to help someone with a balance problem get around the airplane safely.</p>

Air Travel Stories from People Living with ALS

Mr Kent Dickerson	
First Name	Kent
Last Name	Dickerson
Municipality	Guilford township
State	Indiana
Comment	<p>Traveled from Miami to Puerto Rico, and back. American Airlines couldnt figure how to drive chair, tried folding up seat, we watched them from window of plane. On way home, they tipped chair over on side, among I dont know what else. But they had to replace both electric motors, realign chair frame and replace ALL suspension on both sides. Chair is still not right, because it makes a loud screeching sound now when I drive it, the sound was there when I took in for repairs, was ok but I suspect grease wore off, whatever was making that sound. Cost me 2 trips of 6 hours each to get fixed. People this chair is my legs and comfortability. Planes should be made for 2 powerchairs in first row, so we can stay seated in powerchair. Airlines could remove seats very easily if no powerchairs were on flight. I hope you will take this story to heart, because it might be your loved one or family member in this predicament next. Sincerely Kent Dickerson</p>

Philip Hernick	
First Name	Philip
Last Name	Hernick
Municipality	Eagan
State	Minnesota
Comment	<p>I always get assistance Philip Hernick</p>

Mrs. Shirley Jahn	
First Name	Shirley
Last Name	Jahn
Municipality	Sparta
State	Wisconsin
Comment	<p>While traveling with my husband with later stages of ALS..(walks only few steps) Delta stop in DENVER TO SEATTLE. Did not know where the transport chair was until the next day. A siff chair was delivered to the hotel ..spent hours working with the situation as leaving on a</p>

Air Travel Stories from People Living with ALS

cruise. (turns out. Chair was transferred to our Denver to Seattle plane.)
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Mary A Smallidge	
First Name	Mary A
Last Name	Smallidge
Municipality	Trenton town
State	Maine
Comment	<p>My husband has bulbar ALS. Although he is mobile right now, our challenge for travel is his prescription feeding formula. He has a feeding tube in, he requires 6 cartons of formula daily . The individual cartons are in 12 pack boxes.</p> <p>We would need to bring the formula with us. If charged for extra baggage it adds quite an expense to our travel.</p> <p>The formula cannot be stored in extreme heat or cold.</p> <p>We're not sure how we could manage air travel.</p> <p>Sincerely, Mary A.Smallidge</p>

Mr. William Motley	
First Name	William
Last Name	Motley
Municipality	Dunedin
State	Florida
Comment	<p>I for one refuse to fly on any airlines and be manhandled by a couple of inexperienced airline employees. They pick you up in the air by your arms and legs to place you in your seat, risking bruising and injury. This method is completely barbaric and inappropriate. As most ALS patients know, when you're elevated in the air to be transferred. It puts you in the all natural position. As a result, you are more app to defecate or/and urinate. And if it doesn't happen. At that point. How in the world a ALS patient be able to use a restroom on an airline? In my opinion, it's not worth the humiliation, frustration and embarrassment. Not only all of that but, ALS patient could be jeopardizing their own health, safety and welfare, simply by being mishandled, dropped or otherwise injured. Airline services are just not equipped</p>

Air Travel Stories from People Living with ALS

	<p>and probably never will be able to accommodate the ALS patient with dignity and integrity , even if airlines attempted to comply with ADA rules and regulations. I'm sorry, it's just another disgraceful and discouraging way that totally and completely disabled persons have been discriminated against.</p>
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Other Claire Fitch	
First Name	Claire
Last Name	Fitch
Municipality	St. Joseph township
State	Indiana
Comment	<p>Several years ago we flew out of Midway, going to see our son in California. My husband was just beginning to use a wheel chair in his ALS journey. The TSA people had him stand to be searched and wanded --for what seemed to be a terribly long time. That he did not fall was remarkable. On our return trip from the Oakland airport, the TSA was quite prepared for this situation. They first provided him with a cane to assist his standing, while taking his cane for their standard examination. Their checking him personally was professional, considerate and equally as complete as the folks at Midway. Upon our return, I wrote to the Midway TSA suggesting they send their people to Oakland for training. With the relentless pace of ALS, this was our last flight. The employees of Southwest Airlines were very considerate and helpful on both legs of our flight and although we both recognized the need for the TSA in today's world. Oakland certainly had a much better way to handle this situation. Training must be the key.</p>

Mark Weston	
First Name	Mark
Last Name	Weston
Municipality	Lakewood
State	Colorado
Comment	<p>I have heard about wheelchair-reliant travelers who have had real problems with the airlines. Happily, I have not, although I have had consistent problems with hotels and their broken promises at the other end of pretty</p>

Air Travel Stories from People Living with ALS

good flight experiences.

I want to commend Southwest Airlines. My wife (caregiver) and I have flown out of Denver four times in the last 2 years. The gate staff, ground crews, and flight attendants have always been patient and professional when dealing with me and my 385 lb power wheelchair. The chair has never been damaged.

I have, however, experienced difficulty in being transferred onto and off the aisle chairs. Happily, I have never been dropped or cut, but these chairs are too small for my 6'1" 230 lb frame; the crews would benefit from training on safe and comfortable transfer techniques, and the airlines should be expected to provide adequate equipment.

I also believe that the crews would be able to provide even better service if they received orientation on the operation of power wheelchairs. Whether or not this is practical, given the many different types of power chairs, should be open for a serious discussion during any rule making process.

The best solution, of course, would be to design airplane cabins so that we could roll onto the airplane and clip in or be tied down without having to transfer at all.

Respectfully submitted,
Mark Weston
Lakewood, Colorado

Mrs Lisa La Place Knight	
First Name	Lisa
Last Name	La Place Knight
Municipality	None
State	Florida
Comment	We live on an island, so for any health care needed for my husband, we must travel by air to the Tampa VA special unit for spinal cord injuries and diseases. We travel by air every 6 months. We found that the ground crew was unfamiliar with electric wheelchairs, and in many cases, they attempted to lift the 400-

Air Travel Stories from People Living with ALS

pound chair onto the plane. The computer with the joystick must be protected from luggage falling. Several times, the Veterans Administration had to repair damage sustained during travel. What of the unfortunate ALS patients without help from the VA? All parties in each airport have treated my husband with respect and consideration.

Michael Trimis	
First Name	Michael
Last Name	Trimis
Municipality	None
State	Florida
Comment	This needs to be greatly improved: Mandate critical routine hands-on training to all airline staff and contractors who physically assist disabled passengers or handle battery-powered assistive devices and the batteries. Wheelchairs and scooters should be with k baggage. Airport wheelchairs should be available at curbside and at checking desks. Airport wheelchairs should be able to bring people to their seats on the planes and not just to the departure gate.

Mr. Robert Overberg	
First Name	Robert
Last Name	Overberg
Municipality	None
State	Maryland
Comment	I traveled from Baltimore to Orlando. Our wheelchair guy showed us how to remove the most fragile parts of the wheelchair that are most often broken. The Baltimore ground crew were careful to use a scissors lift to pick up my 425 pound power wheelchair to get it onto the aircraft. On the flight home, I watched in horror through the airplane window as the Orlando ground crew loaded my wheelchair onto the baggage conveyor belt and repeatedly pulled on the armrest with all their might to pull it over and lay it down. The armrest broke a week later from metal fatigue.

Air Travel Stories from People Living with ALS

Cassandra Cabrera	
First Name	Cassandra
Last Name	Cabrera
Municipality	None
State	Florida
Comment	My mother loved to travel and wanted to see more of the places she dreamed of visiting when she received her prognosis. But, it was too much of a risk that her wheelchair and powerchairs could be damaged by the airline and at the airport. We heard of it happening all of the time to others.

David Stuart	
First Name	David
Last Name	Stuart
Municipality	Chicago
State	Illinois
Comment	I think it should be a right for disabled people to travel by plane

Marcia Quinn	
First Name	Marcia
Last Name	Quinn
Municipality	Norwalk
State	Iowa
Comment	As a former airline employee we received training on what to look for regarding the type of battery. However there was never a hands on training. Therefore this handling of battery wheelchair became intimidating. You have at least three different areas where airline employees must interact involving wheelchairs at the departure and again three more at arrival city - ticket counter, gate and ground personnel. If individuals are not able to be trained there should be a supervisor with "hands on" training available at each of these locations.

Janie Gobeli	
First Name	Janie
Last Name	Gobeli
Municipality	Kaneville Village
State	Illinois
Comment	Ive always had a good experience traveling

Air Travel Stories from People Living with ALS

	<p>Until my last trip flying home from New York to Chicago. The two employees that were to transfer me to the travel aisle chair to get me down the airplane aisles had no idea on how to transfer or to buckle the buckles. The employees seemed like they did not have an idea or clue what they were doing. In that case they shouldve had more training or someone supervising them to make sure they knew what to do.</p> <p>They did not know how to lift the arm rest in the airplane for the aisle seat. They did not know how to transfer me to the aisle chair and I was sliding off towards the floor. They assumed that I could physically move myself, which I explained I cannot because I am 90% paralyzed from the waist down and I dont have the strength to myself due to my ALS.</p>
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Darlene Martinez	
First Name	Darlene
Last Name	Martinez
Municipality	Tampa
State	Florida
Comment	We have experienced where the airline/ airport does not have the equipment or staff to assist with transporting on and off the plane! It makes traveling very challenging and stressful being a disabled person! Some airlines have told us they are not allowed to assist!

Vivian Garner	
First Name	Vivian
Last Name	Garner
Municipality	Troutdale
State	Oregon
Comment	I have to sometimes go without traveling to various destinations because Im afraid to put my wheelchair or scooter in baggage for fear that it will be broken. There is no way I can afford to fix it, so anything I can do to advocate for us Im happy to do.

Air Travel Stories from People Living with ALS

Joseph Wisboro	
First Name	Joseph
Last Name	Wisboro
Municipality	Worcester
State	Massachusetts
Comment	<p>We lost a friend to ALS and there is no treatment for the disease . She was head nurse at Cape Cod Hospital in Hyannis, Ma . It was a tragedy for a husband and three young boys to lose their mom</p> <p>This has nothing to do with flights but just normal on the ground ambulance care. All three boys grew up without a mother to guide them in marriage and picking of fairer sex and left on their own to navigate the social scene . A fairly frightening experience with no guidance from a parent in terms of parental advice that some older women seek before deciding to accepting an engagement ring.</p>

Mrs. Diane Renzo	
First Name	Diane
Last Name	Renzo
Municipality	Norwalk
State	Iowa
Comment	<p>My husbands als causes leg cramps. I cant always get him a seat with more leg room and at least book an isle so he can stretch out somewhat. Not many choices for seating for him.</p>

Mrs. Ellen Curtis	
First Name	Ellen
Last Name	Curtis
Municipality	Henderson
State	Nevada
Comment	<p>My husband Chris and I flew on Delta to North Carolina where he received an ALS Heroes award at the national conference. Not only do airline staff have no idea how to make a patient comfortable during transfers, they nearly dropped him 3 times.</p> <p>Upon arrival at our destination it was pouring rain. His electric chair was finally brought to our gate a full 45 minutes after we departed the plane. The entire time he was strapped to</p>

Air Travel Stories from People Living with ALS

	<p>the airline aisle chair. He was incredibly uncomfortable with no place for his vent, so he had to hold it in his lap.</p> <p>When the chair finally did arrive it was soaking wet. No one thought to keep it protected from the rain. Thank God it worked, but the cushions were soaked through and he had to ride to our hotel in wet conditions. It was a terrible experience. We never flew again.</p> <p>He was diagnosed at age 50 in 2014 and passed in 2020.</p>
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Kristi Forsythe	
First Name	Kristi
Last Name	Forsythe
Municipality	Kirkland
State	Washington
Comment	<p>There is always some damage to my chair when I fly, which is why Im afraid to use anything more than a transport chair. Weve dealt with scratches, tears and loss of the protective plastic/rubber edges. The worst, however, was when they broke an entire leg off my chair. We were headed to Disneyland and for the first 24 hours (while we awaited a rental chair we had to spend time tracking down and pay for) I had to be propped awkwardly in my chair so both feet could be on the remaining footrest. It was very uncomfortable and really negatively impacted my familys experience.</p>

Tracie Trim	
First Name	Tracie
Last Name	Trim
Municipality	None
State	Florida
Comment	<p>It was impossible to travel after we booked the isles were to narrow for cair. couldn't charge ventilator when needed it was very scary to travel</p>

Air Travel Stories from People Living with ALS

Stacy Inman	
First Name	Stacy
Last Name	Inman
Municipality	Pismo Beach
State	California
Comment	<p>My name is Stacy Inman and I live in Pismo Beach, California.</p> <p>My husband and I traveled from Bakersfield, CA to Houston TX. We were flying Continental Airlines. He had an electronic wheelchair. First of all, no flight attendants came to assist me, a short woman, to get my husband out of his wheelchair and into a narrow wheeled chair which was utilized to have him ambulate down the aisle of the airplane. Another passenger helped me to lift my husband into the "flight chair" so that he could be wheeled down the aisle. Luckily my husband was thin, and therefore, he could make it down the aisle in this contraption without his body hitting the chairs on the aisle. But the real problem came when it was time to maneuver my husband (who cannot move his limbs) from the "flight chair" into an actual airline seat. Since airline seats on the aisle do not move, a 6 point seat belt was placed on him and he was lifted, unceremoniously and dangerously, from the flight chair to the airline chair. The same routine was used to get him out of the airline chair and into the "flight chair" and off of the plane.</p> <p>His wheelchair was banged in the luggage compartment and repairs had to be made to the feet holders.</p> <p>Access for people with ALS who cannot move their bodies is horrendously difficult when they attempt to travel via airlines. No one on the airline knew how to assist my husband, a person with ALS in getting on the airplane or deplaning. Much more training is needed to help those with this terminal disease.</p>

Mrs. Idelle Winer	
First Name	Idelle
Last Name	Winer
Municipality	University City
State	Missouri
Comment	In Jan. 2008, my husband who had ALS

Air Travel Stories from People Living with ALS

	<p>(diagnosed 2005) and I were going to Hawaii on American Airlines. My husband was sitting in the aisle seat, and the flight attendant came barreling down the aisle serving drinks and my husband could not move his left arm to get out of her way. Attendant never acknowledged that she hit him very hard, let alone that there could be a reason why he was incapable of doing so. At the time he was still walking and did not need a wheelchair. Air travel is currently not set up to help travelers with disabilities.</p>
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Susan Day	
First Name	Susan
Last Name	Day
Municipality	None
State	Montana
Comment	We planned an Alaskan Cruise for May of 2023. Planned Fall of 2022. My husband has a portable scooter chair. No problem. Then contacted Alaska Airlines in February 2023 with a question and unknown to us Dept. of Transportation changed the rules and scooters could no longer be loaded on smaller regional planes.

Connie Petersen	
First Name	Connie
Last Name	Petersen
Municipality	Boise City
State	Idaho
Comment	Sometimes getting through security is difficult. One airline really struggled with the battery on my wheelchair. Did not have an adequate ramp for me to get up to the plane. I have also had damage to my portable wheelchair when it has been stowed below and at times it takes 20 to 30 minutes to get my wheelchair from underneath the plane.

Eric Hutner	
First Name	Eric
Last Name	Hutner
Municipality	Ridgefield town
State	Connecticut
Comment	My late wife Robin was diagnosed with ALS in

Air Travel Stories from People Living with ALS

November 2012. She deteriorated from her feet up, and by May 2015 she was full-time in a motorized wheelchair. She had no use of her legs and had some function with one arm. That May, our daughter was graduating from the UCLA School of Law in Los Angeles; we lived in New Jersey. The arrangements I had to make for this trip were staggering, but we were both determined to make the trip and see her graduate. It was a joyous moment that we were able to do so; it was also our last trip together as she died a year later in June 2016.

The nightmare we faced was this: Robin was not a big woman, maybe 52, 140 lbs. But she was paralyzed, with one barely working arm. She was brought onto the plane in a special wheelchair and moved down the aisle. In the process of transferring her to her seat, she was lifted so awkwardly and with such a lack of grace and care, that by the time it was done, her non-paralyzed arm became unusable. Paralyzed as well.

The difficulties I had getting us to the places we needed to go, to clean her face and body, to apply make-up, for the graduation events that we attended, was emotionally and physically overwhelming. Had she not experienced that aggressive handling by the airline personnel, her last trip on this earth would have been so much better. The whole thing was just so sad and the harm done so avoidable. Proper training by the people responsible for helping us would have made an enormous difference.

Larissa Gibbons	
First Name	Larissa
Last Name	Gibbons
Municipality	Forks township
State	Pennsylvania
Comment	They won't take the heavy power wheelchairs and the portable ones are so expensive to buy.

Air Travel Stories from People Living with ALS

Francisco Ibarra	
First Name	Francisco
Last Name	Ibarra
Municipality	Horizon City
State	Texas
Comment	I need help please

Myra Spijer	
First Name	Myra
Last Name	Spijer
Municipality	Shoreview
State	Minnesota
Comment	<p>I Wear 2 hats regarding this: former employee of NW Airlines and Delta as well as now the wife of someone with ALS. We have chosen not to travel by air with the motorized wheelchair since I saw first hand damage done to several passengers' chairs while working at MSP. I also noticed troublesome transfers with well-meaning but not well trained or capable ground staff trying to seat non- ambulatory passengers from an aisle chair to their seat on board.. I had to intervene for passengers on occasion who needed essential ventilators on board. Wheelchairs and other equipment is essential for many passengers including those with ALS. Safe and dignified access to and from airplanes should be a reasonable expectation . Finding your wheelchair damaged at the end of your flight is profoundly problematic and unacceptable. I've heard that Delta is planning on installing room on board to accommodate wheelchairs. That may be part of the solution.</p>

Mrs. Nancy Thompson	
First Name	Nancy
Last Name	Thompson
Municipality	Kenosha
State	Wisconsin
Comment	<p>We had to provide detailed information about the battery for the wheelchair. When going through security, they wanded my friend and then pt her down. They made her lift her shirt to show her Gtube. She was not provided any privacy. When I attempted to advocate for her, requesting they pay her down gently and move to a private area, I was strongly warned to</p>

Air Travel Stories from People Living with ALS

cooperate or else we would not be allowed to proceed through. The United Airline staff. Safely transferred her (she only weighed 85-90pounds) to a narrow wheelchair which fit down the aisle. The wheelchair arrived safely.

Katie Adams	
First Name	Katie
Last Name	Adams
Municipality	None
State	Kentucky
Comment	<p>When preparing for air travel, since my diagnosis, I did a lot of research before hand. I always complete the TSA cares paperwork online and out of the eight flights I have had since diagnosis only once did a TSA officer contact me before my flight and help me through security.</p> <p>I also got on my airlines website and printed out forms about the wheelchair and research height, weight, and battery type of my wheelchair. Again out of the eight flights that I have taken since diagnosis not once did they want this paper.</p> <p>I also filled out a TSA disability notification card that had a blank space to fill out your disability and what all entailed, not once Did anyone look at these.</p> <p>I asked on one of my flights if they had an aisle wheelchair and they said they did not. Luckily I had enough family with me to help me to my seat.</p> <p>I do not travel with my super expensive wheelchair that is much more comfortable for me because of fear that they will damage it. So I suffered the consequences of not having as comfortable of a chair.</p> <p>My vacation would be ruined if they damaged any of my equipment, so flying always gives me anxiety. I wish it was better for people with disabilities.</p>

Air Travel Stories from People Living with ALS

Mrs. Sally Weber	
First Name	Sally
Last Name	Weber
Municipality	None
State	North Carolina
Comment	<p>My husband has ALS and has a quantum edge power wheelchair that is very heavy and expensive. We have flown several times with it and each time it is a harrowing experience. Well we have never experienced damage to his chair. I also take great precautions before boarding to mitigate any damage which takes time and is not always welcome by the gate attendants.</p> <p>We have run into some workers who had no idea how to get it on the plane and others who were very experienced at it, it is not consistent. The worst part for me is trying to get everything that is loose off of it and protected before they take it away and are able to take my husband to his seat. It is stressful and a nightmare.</p> <p>The worst part for my husband is being transferred from his chair to an aisle chair and then to his seat. They don't do it with dignity and care. It's all about speed and just perfunctory business. It is humiliating and degrading to my husband who spent all his business life traveling on the same airplanes and same airline.</p> <p>I applaud the work being done to get seats available on planes for all wheelchair bound travelers to be able to stay in there own wheelchair and be locked in place and be safe. That would make life and traveling so very much easier. Right now I don't know that I would do it again as things are right now.</p>

Kevin Walsh	
First Name	Kevin
Last Name	Walsh
Municipality	None
State	Maryland
Comment	it was sad.

Air Travel Stories from People Living with ALS

Mr. Tommy May	
First Name	Tommy
Last Name	May
Municipality	Pine Bluff
State	Arkansas
Comment	<p>1) I travel from time to time using my wheel chair that is more flight friendly. Ive had occasions where my connection did not get my chair transferred, thus had to have another chair delivered to me at the Little Rock Airport. My lost chair did find me and was delivered to my home in Pine Bluff from Little Rock.</p> <p>2) Ive had a single situation in which my scooter was damaged and could not get it operational, thus had to have it picked up.</p> <p>3) I have had a situation in which my chair was apparently sent on another airline and was not returned to my interim destination for two days. I left the location for a destination approximately 100 miles away. The airlines did find the chair and had it delivered on the third day.</p> <p>4) My greatest frustration is the lack of space between seats on each side of the isle. I require an Isle chair which is rough at best, especially if in a hurry. Again, other than the tight squeeze it is often a challenge with having people available to handle the isle chair (not significant issue).</p> <p>5) I do want to give some credit to the airlines for trying to do their best. I know it is a challenge. Generally speaking, the problems could be resolved by providing or reserving seats immediately behind the first class. In a small airplane, there is very little that can be done.</p> <p>6) Finally, one of my biggest challenges is going to the restroom if it is a lone flight. There is not isle chair on the plane, thus I have to hold on to my wife back to get to the restroom, and generally speaking I must be first class to make the rest room accessible.</p>

Air Travel Stories from People Living with ALS

Lilian Mabry	
First Name	Lilian
Last Name	Mabry
Municipality	Hurst
State	Texas
Comment	Without the help of federal funding and continued medical innovations, we will only have a year and a half remaining, with our dad and husband, Garry! We want him to have the best quality of life possible and to continue to live as normal as possible. Travel can inspire his courageous fight to live. So, we plead that you please make ALS and all it's consequences, regarding quality of life a HIGH priority!

Jerry Stalls	
First Name	Jerry
Last Name	Stalls
Municipality	Cary Town
State	North Carolina
Comment	My name is Jerry Stalls with Stalls Medical and Adaptive Vans Inc. We are a complex rehab business providing custom manual and power wheelchairs as well as accessible vans and home modifications. We have been in business for 34 years and one of our branches is Cary, NC which is close to the RDU airport. For many, many years we have received calls and request to repair manual and power wheelchairs for people traveling and unfortunately their equipment gets damaged, some significantly. We have conducted numerous in-services to help the staff understand various aspects of sensitive electronics and features that can easily get damaged if the chair is thrown around or mishandled. The problem there is there's a lot of turnover, so by the time you train people correctly to load and unload equipment they move on to another position or another company. There are many planes that the cargo opening has a height of 29" which means it has to be loaded on it's side when it enters the cargo space then there's no way to secure it which means when there's turbulence the chairs gets thrown around the cargo compartment hitting other objects resulting in damage. We have shared tips with our customers that other disabled customers have

Air Travel Stories from People Living with ALS

	<p>tried and had success in protecting their chairs. This may include bubble rap around the joystick, not removing gel batteries because there's no chance of acid spills, removing leg rests etc. Hope this helps.</p> <p>Jerry Stalls Stalls Medical Inc.</p>
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Timothy Sullivan	
First Name	Timothy
Last Name	Sullivan
Municipality	Farmington Hills
State	Michigan
Comment	I have been lucky because my ALS is chemical/work related I worked for an aerospace company in grand rapids

Mrs. Linda Martin	
First Name	Linda
Last Name	Martin
Municipality	None
State	Washington
Comment	My problem was the use of the bathroom. I realized there is limited space on a plane but some help and training would help getting in and out of one. I dont mind waiting for my walker or wheelchair but they should have some training on how to help get it set up for you . I know its not easy to get them up and ready with others waiting to leave the plane. I have been lucky not to have had a problem with my equipment when I traveled. Thank you for listening.

Mario Rampolla	
First Name	Mario
Last Name	Rampolla
Municipality	Southeast town
State	New York
Comment	My wife is no longer with us. She passed 17 months after her ALS diagnosis. Sorry, I do not have any air travel comments. She was unable to travel by plane due to her many limitations.

Air Travel Stories from People Living with ALS

Ms. Stephanie Hartmann	
First Name	Stephanie
Last Name	Hartmann
Municipality	Safety Harbor
State	Florida
Comment	No nightmares to tell but I stress out if I want to fly to PA from FL to visit sister the sitting make my legs VERY stiff and I sit to the airport then sit for a very long time before I board and pray that there will be no delays

Mark Kary	
First Name	Mark
Last Name	Kary
Municipality	Roanoke
State	Virginia
Comment	I do not present theres a typical ALS patient although Im living with ALS. I do not have a mobility device, but I do have a service dog which is essential for my safety in public. I have had an issue with being seated in places where they have exchanged my preferred seat with room for my service dog to permit other abled people to sit as a larger group. I've also had a flight attendant take me to my seat while Im boarding ahead of abled customers, and then just walk away without giving me the full assistance that I need when they have miss seated me. Most airline personnel are amazing.

Margaret Dresher	
First Name	Margaret
Last Name	Dresher
Municipality	Lansdale Borough
State	Pennsylvania
Comment	A negative experience My mom had ALS and we were traveling to Orlando, Florida as we had done for many vacations and we had a horrible experience when she was very sick with ALS. For being a destination for so many around the world, they were absolutely terrible dealing with my mom. Im her eldest daughter and took responsibility for her as we all went through the security line - we did everything we could think of to prepare in advance given the nature of her disease and progression. The security

Air Travel Stories from People Living with ALS

personnel were downright rude and dismissive, I travel frequently for work and personal vacations so I understand the requirements. I had to argue with the security personnel that she could not stand out of her wheelchair. I had to advocate to be with her as they tested her wheelchair since she could not speak. She was scared and stared at me with these deep stares that I can still see years after her passing. And we/our family, were such strong advocates. It made me sad of those ALS patients that didnt have strong advocates by their side. It should not be this way. We were horrified at how we were treated given her terminal, debilitating disease.

For a positive experience:

Were from the Philly suburbs and Philly always gets such a bad rap on so many fronts.

However, the security staff at the Philly airport were so wonderful. Ive never submitted a comment card for an airport in my life, but I did after this one trip. They were patient, kind, and appreciated her condition and the need to have an advocate by her side. I was pleasantly surprised - they were wonderful and we still talk about the kindness and compassion they showed us back in 2015. It was mom's last trip and they made it easier despite the physical and emotional toll it took on us all.

There is so much training needed to educate people on the unique challenges of ALS, but I also want to celebrate and applaud those that went above and beyond.

The care, education, and compassion needed would be so impactful to those patients and families dealing with this impossible disease every day. We shouldnt forget that those traveling may be celebrating the last family gathering or big milestone and that caring for someone with this disease is devastating, every day. The small acts of kindness to make small things easier go a long way.

Thank you for listening.

Air Travel Stories from People Living with ALS

Mrs. Samantha King	
First Name	Samantha
Last Name	King
Municipality	Hudson town
State	New Hampshire
Comment	<p>A brief flight from Boston to Charlotte, NC to participate in a clinical trial was a nightmare for us. Although we had informed the airline in advance of our special needs, we had to wait an inordinate amount of time for the one airplane transport wheelchair to become available. We were left on the plane over an hour after everyone else had deplaned. Then we find that my husband's chair was disassembled to fit more cargo in the plane, yet not reassembled. The head support had been removed. No one in the airport would take any responsibility to help us. No one in maintenance had tools or even knew what an "allen wrench" was. I blamed myself for not taking a toolkit with me. We waited so long and my husband was in much pain with no head support. Meanwhile, our rental wheelchair van had been waiting hours after our arrival time, and the rental company said they would leave, as the person dropping it off had plans and it was past their working hours. The airport staff told us to get in the van and drive with no head support. I was adamant that it was unsafe and had to fight to find a tool to reattach the head piece. It was super stressful and my husband was completely exhausted.... This is not even mentioning the other issues, of placing my husband in an aisle seat that was routinely slammed into in passing, not having the extra safety belts we had requested, etc...</p>

Kathy McDowell	
First Name	Kathy
Last Name	McDowell
Municipality	None
State	South Carolina
Comment	<p>My husband was diagnosed with ALS in 2018 at age 39. In 2019 he had the opportunity to be seen at NIH (National Institute of Health) in Maryland. We lived in South Carolina but NIH paid for the airfare and hotel accommodations for the trip and for his extensive testing. In</p>

Air Travel Stories from People Living with ALS

addition to treatment, he volunteered to be part of a research group and his health still qualified him to do so. He was unable to walk on his own. He was not in a power chair yet, but we had a transport chair. We were booked first-class and we had contacted both TSA for assistance through the checkpoint screenings as well as the airlines for wheelchair assistance during boarding and in-flight. It was non-stop flights. We did everything we were supposed in advance to notify those concerned and to request help.

Our flight experience, both getting to MD and returning to SC, was a nightmare. No one was prepared for him, were trained to provide assistance, nor were sensitive or polite in his handling. It was physically hard on him and also humiliating. His body, as well as the transport chair, were mishandled. We were treated as an inconvenience to the airlines and airport personnel - rather than first class passengers. The transport chair was not properly tagged to be waiting for us when he offboarded, which caused delays, and it was also damaged during one of the flights. My husband had looked forward to the trip but was so distraught upon arrival to MD that it affected his testing. All he felt was regret for making the trip, and he knew we would have to return home and feared a similar experience which proved accurate with similar difficulties.

Going over, the airline/airport could not provide either an aisle chair nor a straight back for his use for boarding. They wanted him to try and walk, which was an impossibility. After much delay, a male airport employee picked him up and carried him on board to his seat. On the return flight home, a straight back was available but no one was skilled in its use. The straps were not secured correctly, and it was a scary for my husband. I stood helpless, watching how roughly he was handled throughout the process. The only good thing was it was first class seating. If he would have had to go through the aisle it would have been far more dangerous. We were also lucky he did not need the restroom during the flights.

Air Travel Stories from People Living with ALS

Although accepted into the NIH research program, we never returned to MD and that trip was the last time he flew. In 2020 he received his power chair and could not fathom traveling by air again (despite Steve Gleason indicating it was possible). Maybe only for the extremely wealthy who travel with full-time help. For persons with ALS, they end up living in their expensive power chair - which is invaluable to them. It absolutely cannot be damaged or lost.

In 2021, my husband died of ALS at 42 years of age. I would never recommend air transportation for someone with ALS, not even to receive medical treatment, with current standards. That is a very sad reality.

Kathy L. McDowell
(on behalf of Booker T. McDowell III, Deceased)

Christopher Stone	
First Name	Christopher
Last Name	Stone
Municipality	Los Angeles
State	California
Comment	<p>TSA and DELTA tried to rip me off my flight because they said I was intoxicated. I had ZERO to drink, AND in my Delta pre-boarding notes, I put down that I have ALS, they chose to ignore it because of how I spoke. It was hurtful and embarrassing as TSA yelled at me. This is CLEAR discrimination.</p> <p>Kind regards, Christopher Stone</p>