

# Flying with ALS: Power Wheelchair and Ventilator

The below is an example of the ideal process used for Steve Gleason when he flies. This covers flying with both a power wheelchair, ventilator and other equipment.

**For the most successful flight, communication on every level is key:**

1. Prior to the flight, there's a disability service called TSA Cares that you should call and coordinate assistance to help you get through the check-in and screening process. Call the number up to 72 hours in advance: 1-855-787-2227. Again, this is just for assistance in getting through TSA, but it is always helpful.
2. Once through TSA, you will be on your way to the gate. Once at the gate, it is best to speak to the people at the gate desk, and let them know our boarding procedure. All people are unique in how they prefer to be moved, but for us, Steve is the first one on the plane and the last one off. We “drive” Steve in his chair to the plane entrance and we manually transfer him directly from his chair to his seat on the airplane. It's easiest with first class seats, as the seats are larger, but it's not always possible or affordable. Also, if the flight is booked well in advance, bulkhead seats are also simpler and can sometimes accommodate a tablet and have more leg room. Once Steve is settled on the plane, a second caretaker takes the chair to the elevator to have it brought down on the tarmac to be loaded on the plane.

**COMMERCIAL FLIGHT PROCEDURES (using Steve as an example):**

**1. CARRY ON ITEMS:**

- a. Cof Assist
- b. Mouth Suction
- c. Emergency backpack  
\*\*The above 3 times, we have at all times, anywhere we go.
- d. Separate backpack with the following items to help get Steve comfortable once on the plane:
  - i. 3 medium sized towels - these are sometimes placed under Steve's elbows if they begin to hurt. Towels are also used to help push Steve's head more forward as his head is normally positioned a little too far back.

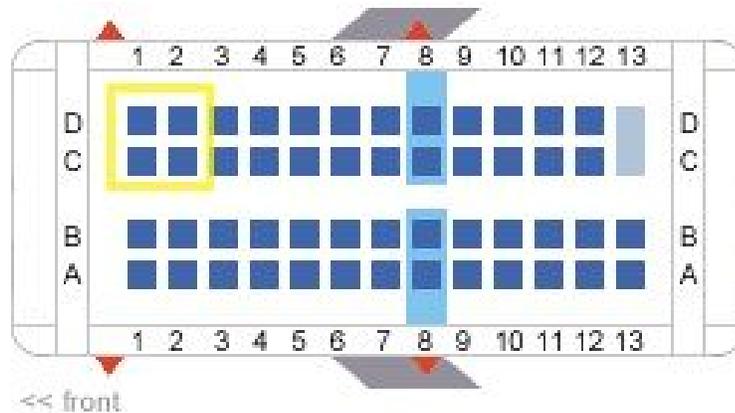
- ii. Miniature pillows - these are similar to the medium sized towels. Normally Steve's butt will start to hurt, so we will slide these under both cheeks to give more support.
- iii. Ventilator charger
- iv. Tablet Charger
- v. 2 piece tablet mount - we set this up once we are in the air and captain gives the clear for smooth sailing.
- vi. Scarf to hold Steve's head in place during take off/landing. The caretaker/person sitting in the seat behind Steve puts scarf over Steve's forehead and holds scarf like horse reins to keep head in place).
- vii. We also carry on an extra vent and backup tablet just in case anything goes wrong with the ones we are using.

## **2. GETTING THROUGH TSA:**

- a. As mentioned above, prior to the flight, we recommend calling the disability service, TSA Cares, for assistance getting through the check-in and screening process. Call this number up to 72 hours in advance:  
1-855-787-2227
  - i. Normal procedures
  - ii. They will normally check the chair and ask a few questions about it, but we haven't experienced any hold up here.
  - iii. Just a plan for a little extra time for them to check the chair

## **3. LOADING ON THE PLANE:**

- a. To load, we are the first ones to board the plane. We will board as soon as the plane has been cleaned off by the cleaning crew. Usually about 10-15 minutes before they begin to board everyone else.
- b. First class seating is ideal - 2 seats next to each other for Steve and caretaker. Economy/Business seating works as well, but is just less space to work with and there are often 3 seats and not 2. When sitting in First Class or Economy, 1 seat directly behind Steve or person with ALS is a must for second caretaker and to store the vent and hose if possible. If you can, have the 4th seat behind 1st caretaker, it makes it more helpful, but not a necessity. Seating as below in yellow square:



- c. We drive the chair down the terminal and back in at an angle next to the plane entrance. If you are facing the plane entrance, Steve and the chair are off to the left side of the entrance, leaving space once we lift Steve out of the chair to enter safely on plane.
- d. Before loading, we lean Steve's plane seat back, lift headrest all the way up, and observe area.
- e. Tie Steve's pants at the waist so they don't fall during transfer.
- f. Next, we have two lifters who physically lift Steve out of his chair and carry him on the plane. One lifter take the top part of the body and the other lifter takes his legs. A third person is needed to transfer vent to seat to have ready to place back on once we sit Steve in his seat. The 3rd person can be an airline employee or service worker.
  - i. How to lift:
    1. One lifter stands on side of Steve (Steve's left side), leans him forward and grabs under armpits. Other person grabs under Steve's legs, just above the back of his knees (hamstring area).
    2. Lifters count out lift and lift Steve up and over left armrest. Lifters carefully and quickly carry Steve on plane to seat. Be sure to watch for his arms hitting anything on the way in.
    3. Once to the seat, lifters set Steve down making sure his hips are back in the seat, like a normal person would when sitting down.
    4. Vent is attached and placed behind Steve's seat (under his seat)
    5. Steve's elbows are positioned on the armrest with hands on thighs.
    6. To finish getting Steve comfy, we use letterboard and he lets us know what adjustments need to be made.

7. Vent can be plugged in. Tablet charger and tablet mount are kept with caretaker sitting next to Steve. Coff is usually kept out the bin. Mouth suction and emergency backpack are placed in bins above--still easily accessible.
8. Buckle seat belt, make sure it's snug.
9. Keep extra towels/pillows easily accessible for inflight adjustments.

#### **4. GETTING CHAIR UNDER THE PLANE:**

- a. Remove tablet and have someone bring on plane to the cargo hold.
- b. Caretaker not working with Steve will drive chair to the elevator to be brought on tarmac. Upon giving the chair to the workers who will load it, caretaker removes omni screen and shows workers how to manually roll the chair. Caretaker also shows workers where to lift the chair from to avoid damage to the chair.
- c. Caretaker also leans seat back all the way and tucks feet rest all the way in.
- d. Just be adamant on the handling of the chair to avoid any misuse.
- e. Headrest is also taken off the chair and kept with us on the plane
- f. Tablet mount is removed and placed in the seat
- g. Speaker is also brought on plane

#### **5. IN FLIGHT:**

- a. Before take off, caretaker behind Steve will put scarf over Steve's forehead and hold it like horse reins to keep Steve's head secure during take off.
- b. Once smooth sailing, set up tablet mount and tablet. Plug tablet into charger.
- c. Caretakers be alert for any adjustments
- d. For landing, place scarf back over Steve's forehead to hold head in place during landing.
- e. The caretaker sitting next to Steve will usually place their arm across Steve's chest during landing to keep him secure.

#### **6. ONCE LANDED AND GETTING OFF THE PLANE:**

- a. Person retrieving the wheelchair will be the first one off. Notify crew they have the chair under the plane they need to get up to the plane entrance.
- b. To save some time, you can also notify crew of your situation and need to get off plane first so they are able to assist you with this.
- c. Once everyone is off the plane, position wheelchair the same way as when loading. It is best and easiest to keep headrest off until immediately after Steve is back in his chair.

- d. The same way we loaded Steve, we also exit him off with 2 lifters and a 3rd person handling vent. Take all carry on bags and place them in the terminal hallway. Make sure area is clear.
- e. Once back in chair, get situated, then breathe and relax. You did it!

**\*\*Something to take note of when dealing with getting the chair safely under the plane and off the plane\*\***

**We've experienced 2 different situations:**

1. We're allowed on the tarmac to help load the chair with the workers. This is ideal, as you are the one handling the chair and getting it under the plane safely. We usually explain this to the workers at the gate that it's best for us to go down on the tarmac and help handle the chair. It makes it easier on your workers and for us to be sure the chair is not damaged. Sometimes they allow it, sometimes they don't. Just be confident during this conversation and really stress the fact that it helps everyone out if someone is allowed to help with the chair. Mentioning the complexities of the chair is also helpful.

**\*\*It also helps to ask for someone with the "ESCORT BADGE" to assist you in getting down on the tarmac.\*\***

2. If we're not allowed to go on the tarmac, we have to teach the employee we hand it off to how to manually lock and unlock the chair. We show them points to pick the chair up from. We also disengage the power to the chair, and recline the seat all the way back so it can fit under the plane. We have also attached notes to the chair.

- One note we put on the armrest that basically says, "Hi, Thank you for taking care of my chair. Please leave everything as is. Refer to the instructions next to the right tire for further handling." The note by the right tire is by the manual locking system. It instructs the workers how to unlock and lock the chair. We are sure to really stress these points and make the sure the worker understands how important it is to not damage the chair.

**\*\*One thing to note whether or not you are able to help is to recline the chair all the way back before loading it under the plane\*\***

- Also, we remove the headrest and bring it on the plane with us. We take the tablet mount down and lay it in the chair prior to putting it under the plane. The tablet also comes on the plane with us.
- From there, once on the plane, we inform the flight attendants we have a power wheelchair that is 350 pounds under the plane that we will need to assist taking it off when we land at our next destination. We tell them we are the 1st ones to exit the plane so we can make our way down to help unload the chair. We then ask if they can call the gate in advance to let them know about the wheelchair and we will assist them when we land.

Usually, the captain can make this call, but you have to go through the flight attendant to ask the captain to call in advance.

Once landed, whoever is getting the chair is the first off, and heads out to the people at the gate to let them know about the wheelchair and you are there to assist. Again, sometimes you will be allowed to go on the tarmac, sometimes you will not be. Either way, if you let the worker know it's a heavy wheelchair, you can give them instructions for handling it that they can relay to their team unloading the chair. Also let the workers know the chair will need to be brought up the plane entrance as you will need it to exit the plane. Once everyone has exited the plane, drive the chair up the entrance where you will transfer and be on your way.

- Again, the main thing is communication. Be sure that each step of the way, everyone knows you have a power wheelchair that needs your assistance to load and unload and its important that it does not get damaged. Be sure to stay on them and monitor every step of the way. Hopefully this helps and makes sense. Please let us know if you have any further questions!

Steve's power chair will only fit on a couple different types of planes. One is a Boeing 737 and then Airbus 319/320. When booking tickets, make sure you book with either of these planes as other planes will not be able to fit the wheelchair. We understand others have flown on different and smaller planes, but we have not been successful getting his power wheelchair on a smaller plane. It is really important to know the measurements of your power wheelchair and communicate them to the airline if you have any questions.

Lastly, if you have multiple stops and not a non-stop flight, added communication with the airline and duplicating the process is key. Steve has only flown 4 hours on a non-stop flight, so we cannot speak to longer flights on a vent.

The goal of this information is to provide insight into how Steve Gleason is able to fly commercially. There is no guarantee this will work for everyone, but we hope it inspires others to consider that there are options.