

Flying While Using a Vent: A Survey of Ventilator Users

International Ventilator Users Network (IVUN) (ventusers.org) wants to understand the depth and the breadth of problems you experience when flying worldwide while using a ventilator. Our ultimate aim is to improve the ability of users of home mechanical ventilation to be able to travel as part of living independently.

If you use a volume, bi-level and/or multi-mode ventilator, we urge you to complete this survey. Our goal is to determine how widespread and serious the problems of traveling with a ventilator are, and if the ventilator user community wants us to work to tackle these problems. We request that you complete the survey even if you think that you will never fly. There are questions for you. The survey will take about 10-20 minutes depending on your experience. Please pass this survey on to other ventilator users.

We want your experiences and opinions if you use a volume, bi-level and/or multi-mode ventilator. If you use CPAP only, please do not complete this survey.

1) In what country do you live?

If you live in the US, in what state do you live?

2) I use home mechanical ventilation:

- 24 hours/day
- At night
- When I rest or nap during the day

3) I need to use my ventilator during flight:

- Each time I fly
- If the flight is longer than 3-5 hours
- If the flight is longer than 6 hours
- I anticipate that I will need to use a ventilator on a future flight

4) I need oxygen:

- Each time I fly
- If the flight is longer than 3-5 hours
- If the flight is longer than 6 hours
- I do not use oxygen when I fly (skip to question #5)

Have you had problems using oxygen on board?

- No
- Yes

If so, explain:

5) When was the last time you flew and needed to use your vent during a flight:

Within the past year

1-2 years ago

3-5 years ago

6-10 years ago

Never. Why not?

No need

Too much hassle

Too expensive

Other:

6) If there were no hassle, how many more times a year would you travel?

0

4-6

1-3

More than 7

7) Have you ever been denied a flight because you wanted to use your ventilator while flying?

No (skip to question #8)

Yes

By (what airline)

wanting to use (what ventilator)

in (what year)

What reason was given?

How much time in advance were you informed that you would not be permitted on the flight?

What other options for travel were provided to you?

8) Have you had any positive experiences using your ventilator while flying?

No (skip to question #9)

Yes

What factors contributed to its success? Check all that apply.

Pre-planning

Airline gate staff

Physician input/cooperation

Airline flight attendant

Manufacturer certification letter

Flying companions/personal attendants

Airline booking staff

Other:

9) Why do or did you travel by plane? Check all that apply.

- Job/Employment
- Volunteer work
- Holiday/Vacation
- Sports (eg: wheelchair hockey competition, international dancing contest, etc.)

Other:

10) When was the last time you flew while carrying, but not using, a vent?

- Within the past year
- 1-2 years ago
- 3-5 years ago
- 6-10 years ago
- Never (skip to question #11)

Did you experience any problems with the airlines?

- No
- Yes

If so, what?

Did you experience any physical problems during the flight?

- | | |
|---|--|
| <input type="checkbox"/> No | <input type="checkbox"/> Shortness of breath |
| <input type="checkbox"/> No, but felt insecure & unsafe | <input type="checkbox"/> Abnormal heartbeat (too fast, too slow) |
| <input type="checkbox"/> Headaches | <input type="checkbox"/> Lightheaded |
| <input type="checkbox"/> Unusual coughing | <input type="checkbox"/> Unable to stay alert/awake |

Other:

11) Did you know that to fly while using a vent in the US, the vent needs to be inspected and certified? This process is done by the manufacturer.

- Yes
- No

What type of vent do you use?

Is your vent type certified?

- Yes
- No
- Don't know

Do you have a copy of the certificate(s) that certifies your ventilatory equipment for use during flight?

- No
- Yes

If yes, how did you get it?

Do you have any documentation or certificate for the use of the internal battery of your ventilatory equipment? No Yes

If yes, how did you get it?

Do you have any documentation or certificate for the use of the external battery of your ventilatory equipment? No Yes

If yes, how did you get it?

12) Below we describe the current "rules" for flying as we understand them. Please review them and give us your opinion as to the next steps that should be explored. (FYI: it appears that many policymakers and other groups think that use of a ventilator and use of oxygen are the same thing.)

In the United States, a Department of Transportation publication states: Carriers are not required to provide the following services or equipment, but should they choose to provide them, they may require 48 hours advance notice and a one hour advance check-in: Hook-up for a respirator to the aircraft's electrical supply.

In European Union documents, there is no specific mention of the use of a ventilator during flight. The most relevant wording states that disabled people "not (be) refused transport on the grounds of disability or lack of mobility, except for reasons which are justified on the grounds of safety and prescribed by law. Vent users report that, in the EU documents, "safety" is not defined nor are the regulations it applies to.

Please check all of the following that represents your opinion.

- Regulations must be changed to *require* the hook-up on all commercial flights.
 - The EU regulations should be more clear.
 - While "messy," the rules give me the option to "negotiate" with the airlines.
 - If IVUN addresses these problems with the airlines, I fear the result will be that the airlines will choose NOT to accommodate the use of ventilators on flight.
 - Since more and more planes have outlets for computers, we should be able to use an outlet for our ventilator if one exists. It should be an automatic option.
 - The airlines need to do a much better job of educating their staff about use of ventilators on a plane.
 - It would be nice to clarify the regulations, but it is not a high priority for me.
- is much more important to me as a user of home mechanical ventilation.

13) Please share any additional information you can give us so we get insight into the problems people with ventilation experience when travelling by plane. You are not required, but it would be helpful if you included your name and email so we can ask follow-up questions.