

# Ventilator Users Speak

IVUN receives numerous questions from individuals with differing backgrounds and for different reasons. Some are authors, columnists, students. Others are ventilator users, family members, health professionals, personal attendants, home health care companies and manufacturers.

A health professional reader of *Ventilator-Assisted Living* reports that he likes the newsletter because it lets him know what his patients are thinking. Here is a question we recently posed to our members:

**Do you consider the machine that you use to assist with breathing as life support? If not, what would be the connotation if it was called life support?**

“That is an interesting question. I really don’t know, and I don’t want to take myself off the high span BiPAP to find out. What I do know is that I do not breathe adequately when asleep to support basic health needs without it. The real question is whether sleeping without it would cause more hypoxic heart damage, which has already happened, or progress to hypoxic brain damage, or would I simply progress to not waking up. Life support is usually considered to be what is needed fulltime, whether awake or asleep. I breathe adequately when fully awake, but not when tired or asleep. So when awake, it is not required for life support. But asleep, for me I do consider my BiPAP to be life support.”

“The LTV950 ventilator I am using now is certainly life support. If I was without it I would first suffer by not getting adequate ventilation and soon would be in respiratory arrest. Brain damage and heart stoppage would follow.”

“I hadn’t thought about my BiPAP in this way before, but it really is life support. I doubt that I could get a night’s sleep without it, and without sleep, one can’t operate as normal.”

“Life support, as I use the term, in its primary sense, refers to things that are needed continuously – without which life ceases more or less immediately. Effective access to oxygen is an example. So for some people, the machine I use to assist with breathing could be life support in this primary sense. But since I don’t need it continuously, for me it is not, because I could survive for 24 or 48 or 72 hours without it. In a secondary sense, however, the machine I use is ‘life support’ for me in the same sense that insulin is life support for a diabetic. You can throw me in jail for a day or two without it, and I would probably survive. But eventually I would die, and it wouldn’t be too long before that happened. In a tertiary sense, the machine I use, as I use it, is ‘life support’ for me in the same sense that water is life support.”

“Life support? This gets complicated the more I think about it. I can still breathe on my own for short periods so, if my vent failed, I would still live ... at least for a while. I would be tired, but I would live.”

“If I’m speaking to a general audience, I say that I’m ‘breathing with mechanical assistance.’ But I also use a power chair for mobility, so my mobility is enhanced, ‘with mechanical assistance.’ In news stories about people who have sustained a very severe head injury, the family is often asked to make a decision to remove the person from ‘life support.’ This could mean several interventions: hydration, nutrition, etc. But this usually means the removal of a ventilator. I guess my answer depends on the person I am addressing. To a physician I might use the term ‘life support.’ To a stranger, or a lay person who is asking out of curiosity, I’m sure I would use a less medical term. ‘Life support’ carries too many negative connotations. This is probably a more long-winded answer than you wanted. It gave me something to think about. I would not ordinarily use ‘life support’ to describe my vent.”

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“No, I don’t consider it life support. If I could not breathe on my own, I would consider my vent life support. On most days, I only use my vent at night. Though, thinking the question through, if I couldn’t use the vent for a night, I would consider it life support. I could probably make it through one night without it, but would probably be very uncomfortable.”

*“The Stellar 150 and its backup Synchrony are life support. I would be dead otherwise ... as simple as that.”*

“Life support to me means the person cannot stay alive without it – period! I consider my Pulmonetics as an assist (meaning, with it I can rest my own breathing muscles at night, in the car, on the computer, etc.). Hopefully this ‘rest time’ helps me stay strong enough to breathe on my own when I want to and/or need to. So far, this definition has worked fairly well for me. I do require some vent time daily as well as all night. When I’ve had a very tiring day, I usually spend a big part of the next day resting with the vent. So is mine truly life support? Hmmm. Not by my definition above. Perhaps my Pulmonetics is ‘normal life enabling.’ Whatever that means!”

*“I definitely consider it life support because without it, I would eventually die. And I don’t think it would take long for my heart to give out. There have been times when I was using the vent and thought I would soon die (e.g., when I have pneumonia, an infection or am very anemic). However, I think for many, ‘life support’ means being full time on a vent and being kept alive, often in a comatose state.”*

“My first reaction is that it isn’t ‘life support’ ventilation as I will not immediately die without it ... I can breathe on my own for a period of time. However, I would gradually die as I got more and more exhausted struggling to breathe. My sense of it changes depending on circumstance. In a power outage it is clearly ‘life support’ to me and I present it as such. If a hospital or service refuses me (e.g., airlines), the ventilator is not ‘life support’ because it scares them off.”

“In the non-medical mind, we all know that magazines and TV usually portray ‘life support’ as a ventilator for a newly comatose person who has no ability to breathe without the ventilator and no ability to recover. Turning off the ventilator is often an option being considered by outsiders and is equated with death.

“But the polio/ALS/SCI/neuromuscular community is not comatose. We are very much alive and aware. Our conditions vary in severity, but many of us need ventilators.

“I see my ventilator need as one end of a continuum. Everyone uses machines. We all use cars and smart phones, live in a home heated with a furnace, rely on water pumps, etc. Even our most distant ancestors used rocks and spears, both simple machines. In sealed modern buildings and airplanes, artificial ventilation systems keep everyone alive. So I see human life as enhanced by machines to facilitate living. In my particular circumstance I now require my closest machine to be a personal ventilator.

“The major problem with using the term ‘life support’ is that some segment of the population may see those needing ‘life support’ to be less than fully alive, and therefore think that they have the right to remove the ‘life support.’” ■