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# THE VENT LIFE

## Who Says You're Out of the Game?

You'll find the hardware here also, but the heart of this cover story is lifestyle. To too many uninformed observers, the vent life is a contradiction in terms -- how can you have a decent life when you're plugged into the local utility? Here's rich evidence that life doesn't end after mechanical ventilation from the people who know best -- readers who use vents. They put to rest the vexatious quality-of-life issue, and prove that a vent is just a machine, not an enemy.

# THE VENT LIFE

By Barry Corbet

Once again, we look to the experts – in this case, to people who use ventilators. From what they have told us about the vent life, we can pass on some generalizations.

The biggest single problem vent users face is the outrageous cost of their equipment and care. Many who use invasive ventilation need skilled nursing, and paying for 24 hours a day of that can be a nightmare. A few have trained friends, family and unskilled help so well they feel comfortable with a minimum of nursing care.

The care level may not be a matter of choice. Many states mandate skilled nursing for vent users. That annoys those who feel they can get by with cheaper help, and alarms those who fear their essential nursing will be cut by the current enthusiasm for cost containment.

At any level of care, by the time you throw in a couple of $10,000 vents and a power wheelchair -- and some way to transport them -- you've run up a rather astonishing bill. Consequently, most vent users must rely on Medicare, Medicaid and entitlements. An admirable few can make enough to pay their own medical expenses, but it's a fiercely heroic life they lead.

Can you learn to love your vent? Sure, said most -- it's the breath of life, and it becomes part of you. Others curse their vent as a noisy, cranky umbilical cord to a wall socket. Most gripes are not about the machine itself, but about dependency, the perception of being a burden and lack of privacy. What's the hardest thing about using a vent? It's unanimous: when it doesn't work.

Ventilators are dependable and failures are rare. Yet almost everyone we talked to has a couple of horror stories. The lines of defense, successively, are "frog-breathing" for those who can do it, a spare vent, the Ambu-Bag and calling 911. Some admit to a lingering uneasiness about it.

Our experts -- even those who have spent several decades on a vent -- are generally in good health. The most common complaint is needing more time on the respirator. Most feel they've learned enough over the years, and are good enough at reading their own bodies, that they can tell when they – or the vent -- have a problem.

The MDA comes in for some criticism, this time for its lack of support for mechanical ventilation for people with Duchenne muscular dystrophy. Why, vent users ask, does the MDA feel their quality of life is so low that ventilation is a waste?

That's a point everyone agrees on – quality of life should be defined by the person living that life, not somebody else. Not anybody else.

*>The Quality of Life Issue*

Is a reasonable quality of life possible if you use a ventilator?

Many doctors and allied health professionals don't think so. The most common reason that MDA clinic directors cite for discouraging ventilator use is poor projected quality of life. But the health professionals' low opinion of the vent life is not shared by the people living those lives.

If your doctor, nurse or even your family and friends are telling you that your life will be terrible if you go on a ventilator, hand them a copy of these studies. And tell them to go fish.

* A 1992 life satisfaction study by John Bach compared responses by 80 Duchenne muscular dystrophy ventilator users to responses by 273 MDA clinic directors. The clinic directors significantly underestimated the users' reported life satisfaction. The study concluded that patients who were perceived by physicians to have a poor quality of life were less likely to be offered assisted ventilation.
* In a 1992 study by Bach and Campagnolo of 395 ventilator-assisted people who'd had polio, 86 percent reported their lives were characterized by hope, value, freedom and happiness. Forty-two percent of the ventilator users were employed and 39 percent were married. Yet again, the health professionals used for controls underestimated the life satisfaction of people using ventilators and overestimated the difficulties. It was concluded that physicians should be aware of their inability to accurately gauge the life satisfaction of individuals and should not use their perception of poor quality of life as a reason to deny ventilator assistance.
* In a 1994 life satisfaction study by Bach and Tilton, 42 ventilator-assisted quads and 45 autonomously breathing quads were compared to a control group of health care professionals. Both groups with spinal cord injury reported higher life satisfaction ratings than were predicted by the controls. Notably, the ratings for those who used ventilators were higher in some areas than for those who didn't -- the former were dissatisfied with sexual function only, whereas the latter were dissatisfied with their jobs, health and sexual functioning. Vent users said life was friendlier, more interesting, more enjoyable, fuller and more hopeful than non-vent users.
* A 1992 study by Whiteneck, Charlifue and Frankel of people with spinal cord injury at least 20 years post-injury showed that those using ventilators rated their quality of life higher than those who didn't, and had a lower rate of suicide ideation.

The above information was taken from "Independent Living and Quality of Life Among Persons Who Use Ventilators," an in-press book chapter by Margaret A. Nosek, Ph.D., and S. Ann Holmes, M.D. Both authors are ventilator users themselves.