

I.V.U.N. NEWS

International Ventilators Users Network

Fall 1990 ■ Volume 4, No. 2

Breathing Failure in ALS & Handling Emergencies

by Barbara Beal, RN, MN

A frequent complication of ALS is breathing failure. Individuals with ALS hear all sorts of stories about it — some of them fearsome. This article is written in the hope of allaying some of the fears with facts drawn from experience.

Tim was diagnosed with ALS in 1987. He was a truck driver with large hands and powerful muscles. Carrie, Tim's wife, said that Tim knew almost nothing about ALS after the diagnosis until he wrote in for literature. He read all of it, and being a self-contained man, asked few questions.

However, he was vehement that he did not want any life support devices if and when the time came. In fact, knowing that he was going to die and that Medicine could do nothing for him, he figured that he would not need medical help any longer. So he got his affairs in order through a lawyer, signed a Durable Power of Attorney (DPA) for Health Care appointing his wife as his "attorney-in-fact" to make decisions for him in the event that he might not be able to speak for himself. Then he cancelled his health insurance — too expensive and certainly not necessary.

One day, Tim fell in the bathroom and it took both Tim and Carrie a miserable hour to get him, crawling, back to the couch, up on his haunches, rocking back onto a low stool and onto the couch. It did not occur to them to call for help.

The next week, Carrie noticed Tim's breathing was kind of hard. He also had a slight fever. Accustomed to Tim taking the lead in their marriage, Carrie did not call the doctor when Tim indicated that she should not. He had slowed down on drinking fluids. Then, on Friday night, he motioned to Carrie to open the glass doors since he couldn't get enough air. Carrie said, "Don't you want me to call the paramedics?" Within 30 minutes, Tim nodded "yes."

By the time the paramedics got him to the hospital emergency room, he was passing out. The emergency room (ER) doctor said to Carrie, "He will die in

about 20 minutes unless we give him some life support." Carrie agreed, thinking he meant oxygen. When they allowed Carrie into the ER, she saw the tubes and thought it was oxygen, but in the ICU it became quite clear to her that he was on life support, exactly what Tim had not wanted.

This episode, called rapid onset respiratory failure, was precipitated by a virulent pneumonia that was later discovered by X-ray and blood tests. Tim was treated vigorously with antibiotics and even dopamine to keep him from going into shock.

I saw Tim the following Monday. He was thoroughly awake, and did not like the spot he was in. His color was good and he looked like his old self. There was little visible muscle deterioration. Tim knew it was highly unlikely that he would be able to be weaned from the life support even after the pneumonia cleared. He knew there was no money for hospitalization. In the flurry of the moment, no one had thought of the DPA. Tim's daughter, Marilyn, went home and got it. A copy was placed in his

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Breathing Failure

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medical chart and the original went into Carrie's purse.

The next day, a ventilator tube disconnected, and Tim motioned for a nurse to reconnect him. Did this mean that he had changed his mind about not wanting life support? No. It only meant that he needed immediate help. The pneumonia was clearing but Tim could not take any breaths of his own when off the ventilator. What to do? On Tim's computerized keyboard communicator, he indicated that he wanted to take one day at a time — not decide just now.

(California law allows people to accept or refuse medical treatment. If one is on life support, one can choose to try it alone without the machine. A few people do fine. Some people cannot breathe again on their own. With ALS, the chances of breathing independently again are slim.)

The hospital bioethics committee was to meet on Thursday. Having a committee meet about Tim and with Tim was definitely not his lifestyle.

At 5 a.m., Marilyn called me to say that her father had died at 4 a.m. Somehow, the tube had come out and he had refused to have it put back in. Tim lasted 8 minutes, going unconscious immediately after expressing his wishes to the ICU staff. "He looked very peaceful," Carrie said. She felt those extra days had allowed him to say "goodbye."

What can we learn from Tim's experience? Let's look at the distant early warnings (DEWs) of gradual respiratory failure and discuss what can be done. Years of experience have taught me that most people handle problems better if they know what to expect, rather than sticking their heads in the sand and hoping for the best without knowing. In fact, some problems *never arise* when one knows the facts. Knowledge seems to set up coping processes in the person. Perhaps we are better able to avoid bumps

in the road when we know where the bumps are located.

Gradual breathing failure

Breathing difficulty does not happen to everyone with ALS; but if it does, it always comes on gradually. The big problem is chest infections which can accelerate the process dramatically. Many people with ALS have gone through this disease with no emergencies. It can be done. There are DEWS (distant early warnings).

Some DEWs

Shortness of breath (dyspnea). Also termed air hunger, this is usually noted first on activity; later on, it occurs even at rest. You think, "I am getting out of shape" or "I am getting old." So you forget about it. Later on, you note that you get winded with less and less activity. Sometimes just turning over in bed can make you winded.

We all have favorite positions for falling asleep. You may notice that this position is no longer comfortable and you get restless. Elevating the head and chest with a blanket folded under the head of the mattress or using an elevated position in a hospital bed can make breathing easier.

The solutions to shortness of breath is to do activity *within* your range. Stop soon enough and rest until your breath comes back. Exercises to strengthen breathing muscles waste precious breath. Don't do them unless the goal is to keep your chest flexible. There is no exercise that can bring back muscles that have lost a good nerve supply. But you can protect your muscles from fatigue.

Changes in breathing pattern. Normally, breathing is super efficient. The diaphragm, largest muscle in the body, does 70-80% of the work. The belly, shoulders, neck, and rib muscles do a minor but necessary job. Think of oxygen as you do gaso-

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links ventilator users with each other and with health care professionals interested in home mechanical ventilation.

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line for your car. Normal breathing uses about 2% of the body's oxygen to perform this quiet constant movement throughout your life. Labored breathing can take up to 50% of your oxygen.

If you are using the smaller muscles more and more, you will tire more easily. Take a look at a person with normal breathing. Then take a look at yourself in the mirror. If you note any differences, ask your doctor or nurse to explain. It may be your body build or it may be a sign of oncoming problems.

Respiratory infections. People with ALS are more susceptible to infections than others, only because they have a harder time clearing secretions (phlegm). ALS does no damage to lungs or heart tissue.

Cough may not be strong enough; there may be a tendency to get food down the wrong way or mucus accumulates. Sometimes infections cannot be avoided. They may occur simply because you don't breathe deeply enough to keep all the delicate areas of the lungs open and moving air. This is called stasis. Resulting infection is termed stasis pneumonia.

What can be done to prevent chest infections? It is important to avoid crowds and family members with colds. Flu shots in the Fall are valuable. Activity and frequent position change help keep the lungs open — even turning in bed helps.

Mechanical aerosol devices can be used under medical prescription with good instruction on how to use them. Water is better than a device if you can drink enough to keep your chest secretions thin. This makes it easier to clear your throat. Sometimes, choking on saliva or mucus cannot be avoided. If you are able to keep your secretions thin by good fluid intake, choking may never occur. If it does, staying relaxed and peaceful is very difficult, but is the best way to restore easy breathing. An open airway is a relaxed airway. If you do get a chest infection, seek medical treatment and antibiotics *early* before it gets a hold on you. This is very important!

Carbon dioxide. Slow breathing failure leads to an accumulation of carbon dioxide in the blood. This acts like slow anesthesia. The slow symptoms are: first, insomnia, then later, increasing sleepiness. You may feel mentally fuzzy or forget things. You find yourself getting irritable and the family may notice a change in your personality. As time goes by, you find yourself napping all day long.

The ventilator — your choice

What if you say "No." Let's say you have oncoming breathing failure and you have decided you do not want the ventilator, should it become necessary. What happens now? Discuss your thinking with those nearest to you who will be affected by your

decision, and with your physician. You should obtain a DPA and provide the physician with a copy.

Eventually as carbon dioxide builds up in the blood the tissues do not get enough oxygen and you will be in slow respiratory failure. You may decide to stay at home and let this happen. Surprising to most of us, this is not a bad way to go. You need to be at peace about your decision — that it is the right one for you.

Should your condition be such that you feel medical attention is needed immediately you may need to go to the nearest emergency room (ER). Either have someone take you or call 911 and the paramedics will come. This does not mean you will be automatically hooked up to a ventilator, even though the ventilator may be the only treatment possible to the physician in the ER. If you still do not want the ventilator, you will need affirmation that the moment has come and receive any medical help, such as anti-anxiety pills to make you comfortable. State your wishes or have your "attorney-in-fact" do so and show your DPA.

Remember the choice is yours.

What if you say "Yes." Now, let's suppose you have chosen to use a ventilator. There are many considerations. The main one is that you will be slowing the clock on your life's end. Do you hope a cure will be found in time for you? Do you have more to do in your life — unfinished business? Perhaps you are afraid to die. Fear can be omnipotent — and fear is a legitimate reason to choose life support. If the time has come and you seek medical help without planning, it is very likely that you will wake up on a ventilator.

Some physicians have opinions about what is best for you. That is O.K. But *yours* is the only decision that counts. One thing for sure, you cannot go on a ventilator without a physician's help — so involve the doctor early in your thought process.

Round-the-clock nursing care from family or professionals will be needed. Ventilator home care will be less stressful if you have insurance to cover the monumental costs.

Conclusion

Knowing your reason for living will help you through decision-making. This sounds nebulous, but it is not. Thinking thoughts about our lives being finite — going to end some day — is not all bad. You can clarify and streamline your life. Decisions made from fear are all right, but decisions made from calm are the best. Knowledge helps prepare you.

Discussing this difficult subject with those nearest to you can build relationships. One woman said,

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For the Shape I'm In, I'm in Pretty Good Shape

by S. Scott Cameron

In 1959 at age 3, I was diagnosed with Duchenne Muscular Dystrophy (DMD). Since 1980 I have been a ventilator user and have experienced many highs and lows.

The real high was when I finally left the hospital in 1980 after seven weeks and many serious setbacks. A tracheostomy had been performed the day after I entered the hospital in respiratory failure and I became a ventilator user. During the fifth week, after being near death a couple of times and not sure how much longer I would be there, I thought I should have just let nature take its course. After I had survived several pneumonias, bilateral pneumothoraces, and periods of extreme mental fatigue and withdrawal, I felt, and my parents concurred, that enough was enough! It was time to go home whatever the consequences.

My very supportive parents did all they could to accommodate me at home and, thanks to the instructions given by Dr. Thomas Petty and the wonderful staff at Denver's University Hospital, they learned to care for me and my LP3s with the intermittent aid of nurses.

At first, trach tube changes were frequent due to a leak in the cuff. It seemed to help when we stopped using a stopcock and then it seemed that the manufacturing of the Shiley trach improved. Whatever the reason, I was able to go much longer between changes, and now the longest I have gone with a trach tube change is seven months.

Breathing Failure

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"My mother and I hated this disease, but we loved what it did for us. We became closer to each other in love than we had ever been." Her mother chose no life support: she was conscious and peaceful to the very end.

Know what you are facing and I can assure you from experience that you will face it better. Your life, as well as your passage to whatever is on the other side of death, will be peaceful if you are prepared.

© 1989 Barbara T. Beal

Editor's Note: Barbara Beal, R.N., M.N., is a nurse specialist in home care of individuals with ALS. This article was reprinted with permission from *Reaching Out*, the newsletter of the Orange Co. Chapter of the ALS Association.

I have always used a cuffed trach tube but have never been comfortable with the cuff deflated so I have been unable to speak for these ten years. For a while I tried deflating the cuff so I could talk, but I was so uncomfortable with the cuff down and with so much air leaking around my trach tube that my speech was not very good. Dr. Petty had anticipated that I could have the cuff deflated except perhaps at mealtimes so I was unprepared for the fact that



communication would be so difficult for such a long period. Actually, my loud whisper is easily understood by those who are around me for any length of time and who take the time to look as well as listen when I am speaking.

Before leaving the hospital and during the first year at home, I tried to wean myself from the ventilator. I was finally able to go as long as three hours but was then quite exhausted and had no energy to do anything else. As I wanted to continue my jewelry-making business, Cameron's Creative Castings, I gave up attempts to wean for longer periods of time. Currently I can be off the ventilator for only short periods of time — 15 minutes at the most.

A mask, safety goggles, and a towel to cover the ventilator circuit were necessary protections when I would grind or polish the silver pieces. Unfortunately, even though my respiratory condition stabilized, the deterioration due to DMD continued and I could no longer grasp the small silver objects or hold the tools. My jewelry-making came to an end in late 1982. Even more disturbing was the fact that my

hand no longer had the strength to work the control on my motorized wheelchair.

In 1984 my father became managing director of the Stanford Court Hotel on Nob Hill in San Francisco. We lived at the hotel for a time and our rooms afforded us a great view of the Bay. Most interesting to watch was the fog surrounding the tall buildings make its early morning departure and then reappear in late afternoon to slowly engulf the city.

December of 1984 was a low period when I was suctioned too deeply and had to be admitted to the hospital because of bleeding. I was hospitalized for observation, but soon discharged as the bleeding subsided.

My second hospitalization in California was longer and more serious. Bowel problems developed into a severe impaction which after tests and X-rays was thought to be an obstruction. Surgery was considered with the understanding that I might not survive it, but on the other hand, I might not survive *without* the surgery. My parents left it to me to make the decision, and they, and I think the doctor as well, were greatly relieved when I decided against the surgery. It was touch and go for a few days, but my condition began to improve and, eight days later, I was allowed to go home.

Through the years, ventilator failure has always been a concern but presented no significant problems during the years in Colorado. We quickly learned that malfunctions were likely to occur every 10-12 months, but Life Products in Boulder would respond promptly. During this time, my second LP3 was used by the bedside and, when needed, transferred to the wheelchair.

In California we found a very reliable medical supply company that would repair the ventilators and allow us to rent a replacement ventilator, usually an LP4 because LP3s were no longer available. Life Products was acquired by Aequitron Medical, Inc., which now manufactures the LP6. We still felt the LP3 was a completely reliable ventilator well suited to home use.

But one of the ventilators malfunctioned — two days after my father died in 1989, another low in my life. Because it was so close to a holiday weekend, we decided that I could get along with just one ventilator for a few days. Of course, the second ventilator stopped working that Sunday. The trusty ambu bag was quickly put into use and my mother "bagged" me for about four hours. We finally located an on-call respiratory therapist who was dispatched with an LP6. Should the bagging not keep me comfortable until the therapist arrived, the doctor and hospital were alerted to the situation. Just as we were about to call the ambulance, the therapist arrived, very competently set up the LP6, and in no time the situation was under control.

Stanford University's Rehabilitation Center re-designed my wheelchair for comfort and installed a sip and puff control. What a wonderful feeling to be able to get around by myself again! I was also introduced to the computer and obtained an Apple IIe. I use a mouthstick and have an adaptive firmware card to eliminate holding down two keys at the same time. The computer has become a vital communication device for me.

Following my father's death, my mother and I decided to return to Denver. We drove our van all the way there, and I withstood the trip much better than anyone anticipated. Our only mishap was a flat tire on the summit of the Donner Pass!

I am currently a patient of Dr. Barry Make at National Jewish Center for Immunology and Respiratory Medicine in Denver, and will soon be getting an LP6. Dr. Make finally convinced us, as so many people have been telling us for years, that the LP3 really is obsolete.

As I recall the highs and lows of these past ten years, I think of my two older brothers. Both had DMD and died from conditions similar to those that hospitalized me ten years ago. The good Lord and medical technology have enabled me to live to age 34, somewhat longer than most with DMD. I hope I will still be around until a cure is found.

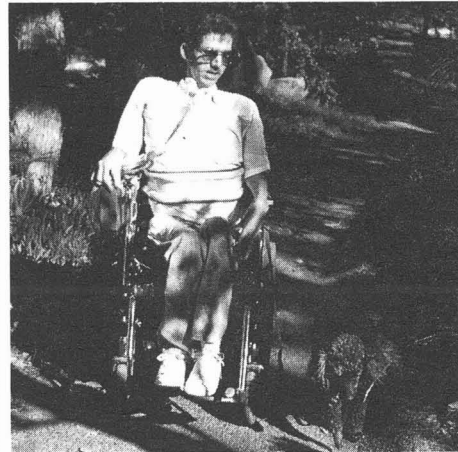
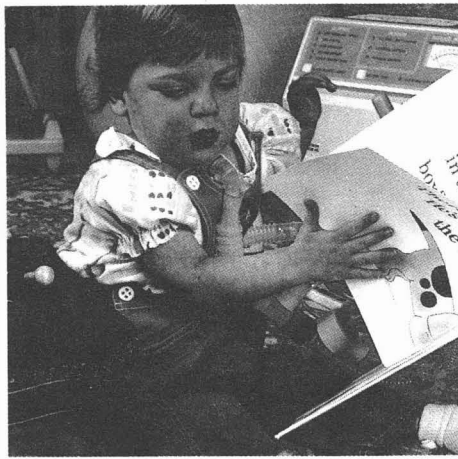
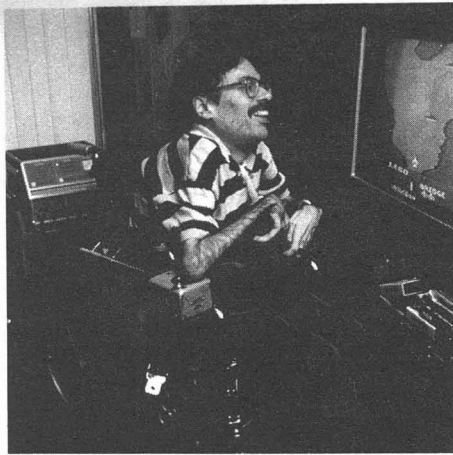
The past ten years would not have been possible without such fantastic parents who took such great care of me and all the supportive relatives and friends who have really cared.

ADDRESS: S. Scott Cameron, 2800 S. University Blvd., #84, Denver CO 80210.

In Memoriam ■ David Muir

David Muir, inventor of a valve that helped restore speech to individuals with tracheostomies, died after an accident on August 30 in Mesa, Arizona. Muir, 28, had Duchenne's Muscular Dystrophy. When he began using a ventilator, he lost his speech and became so frustrated that he studied the equipment he was using and designed a prototype of the valve.

The Passy-Muir Tracheostomy Speaking Valve redirects air flow and allows users to expel air through the mouth. Muir's business partner, Patricia Passy, and her husband Victor Passy, M.D., an ear, nose, and throat surgeon, helped market the device to more than 100,000 people. Anyone wishing to extend condolences to the Muir family should write in care of Passy & Passy, 4521 Campus Dr., #273, Irvine CA 92715.



The Many Lives of the LP6.

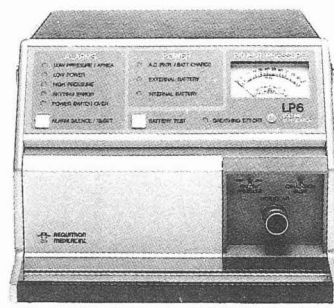
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This directory is a continuing effort to compile longtime ventilator users and health professionals who are experts about and advocates for home mechanical ventilation. Additions, deletions, and corrections should be sent to I.V.U.N., 4502 Maryland Avenue, Saint Louis, Missouri 63108 (314/361-0475).

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*ventilator user
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(continued on page 10)

*ventilator user

**pediatric interest

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(continued from page 9)

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*ventilator user

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Consider Yourself a Home Care Ventilation Equipment Consumer

by Jerry Daniel

You are one of the estimated 4,000-5,000 people in the United States who uses mechanical ventilation either parttime or fulltime. Statistics have proven that for most people using ventilators, life is still well worth living. You are likely to develop personal coping skills and call yourself a survivor.

Having control of your life is important. Medical professionals may refer to you as a ventilator "patient," as a means of identification. As you develop experience and knowledge of the equipment, you become a consumer of ventilators and all of the accessories. You also have choices of the medical professionals who treat you and the equipment supplied to you. In most cases, your care and equipment will be paid for by Medicaid or Medicare. The system will place some restrictions upon your choices, but you still have many options.

There are a few areas in the U.S. with outstanding centers for ventilator patient care, but in most geographical regions, the ventilator user must find a physician or university medical center that is knowledgeable about the problems of long-term ventilator users. If you find a physician you like, but who is admittedly inexperienced with some of your problems, is that physician willing to network with other physicians to give you the best care? If you feel your physician orders pulmonary function tests too often, and you are concerned about costs, you can question or refuse some tests.

State-of-the-art positive pressure ventilators have breaths per minute, volume, and inspiration velocity with split second timing controlled by a microprocessor. They are highly reliable and sell for about \$8,000. Most respiratory home care supply dealers have one or more of these ventilators, such as Aequitron's LP6, Puritan-Bennett's C2800, Bear's 33, and LIFECARE'S PLV100, available for lease.

Some long-term ventilator users prefer the less expensive and simpler units of the early 1980s. These units have fewer electronics and not as many setup options. Units like the PVV, LP3 and LP4, and Thompson suitcase ventilators are slowly being phased out, but are still available if you find the right dealer.

Home ventilators are an expensive consumer item. If you or your family pay for your equipment, you have the right to look for the best possible buy. Used ventilators are available from private individuals, but when you buy a machine under these

circumstances, it comes as is, and you cannot hold the seller responsible for ventilator failure. Liability lawsuits could make such purchases impossible.

There are three major companies who supply home ventilators in most areas of the U.S. They are Glasrock Home Health Care, Abbey-Foster, and LIFECARE. Newer arrivals in this market include HoMedCo and Linde. Many small local home care companies can supply this equipment, but supplying home ventilators is an expensive investment for the small dealer, and some lease the machine from the manufacturer to supply you. Home care dealers who supply ventilators are usually listed in the Yellow Pages under "Oxygen."

If you have a trach, it is one of the most important parts of the positive pressure circuit. Many oldtime ventilator users prefer the metal Jackson trach. The ventilator connection is somewhat awkward, requiring rubber bands to hold it together, but it is a personal consumer choice. There are some excellent plastic trachs available made by Shiley and Portex with disposable inner cannulas and good ventilator connections with swivels to eliminate flex hose kinks. With these, you can throw away the rubber bands. The plastic trachs come in both cuffed and uncuffed versions.

As a well informed, sometimes critical but reasonable home ventilator consumer, you will have an important element of control in your life.

ADDRESS: Jerry Daniel, 4604 Plomondon, Vancouver WA 98661.

Editor's Note : Jerry Daniel, respiratory polio survivor since 1948, is a home ventilator equipment repair vendor for Aequitron Medical, Inc.

Deadline for submission of articles, stories, information, etc., for the Spring 1991 issue of *I.V.U.N. News* is March 1, 1991.

Please send to:
I.V.U.N. News
4502 Maryland Ave.
St. Louis, MO 63108

"On" a Ventilator?

The last issue of *I.V.U.N. News* raised the question of terminology and drew a response from Audrey King, a ventilator user from Canada, whose drawings accompany her thoughts, and from Karan McKibben, whose regular column in *I.V.U.N. News*, "Musings," also addresses the terminology.

Audrey writes, "The words we use conjure images which shape attitudes and consequently behavior. What does "on" a ventilator mean? It suggests a person lying across or sitting on a ventilator! Surely, to be accurate, the ventilator is on the person. Wouldn't it be more correct to say the person "uses" a ventilator? Or is it really the person who uses it? Perhaps it is the health professional and not the patient after all?"

Audrey continues, "Think about the fact that the astronaut is also dependent on complex assistive devices, even life support, in order to live and function in outer space. Yet he is not perceived as defective, sick, or disabled. Rather, it is his environment which is considered alien and unable to meet his particular physical needs. The astronaut is perceived as a competent responsible person who monitors his needs and maintains the equipment he is dependent upon.

"Many ventilator users are such 'responauts.' They consider themselves competent, responsible, and knowledgeable of their needs. They do not regard themselves as deficient or helpless. They perceive the environment to be the problem. Their

physical needs can be addressed and maintained but the environment, both physical and attitudinal, presents enormous barriers to attaining the personal autonomy and independence so necessary for quality of life."

ADDRESS: Audrey King, Hugh McMillan Medical Center, 350 Rumsey Rd., Toronto, Ontario M4G 1R8 Canada.

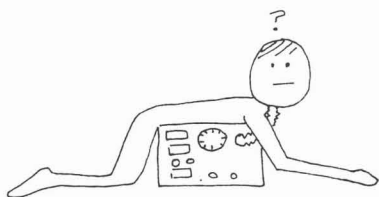
Musings: Into the Wonderland of Words and Ventilators

by Karan McKibben, Ph.D.

In the last issue of *I.V.U.N. News*, there was an invitation to comment on the terminology commonly used to refer to people who rely on ventilators. The main objections to the three terms used most often were then indicated, and they set one to wondering whether there is any terminology that is unambiguous and at the same time politically sensitive to the concerns of the readers of *I.V.U.N. News*.

The term "on the ventilator" illustrates well some of the problems. In a hospital setting, where the focus of communication is on immediate physical concerns about bodies, machines, and drugs, referring to a patient being either on or off the ventilator

"ON" A VENTILATOR?



OR ... "UNDER" A VENTILATOR?



Drawings by Audrey King

seems as acceptable as referring to a patient being on or off a specific drug. However, if the context is broadened to include the possibility of a future life outside the walls of an institution, the term becomes not only crude but quite illogical. One can hardly refer to someone living long and happily "on the ventilator" without insinuating that being "on the ventilator" may be something akin to being "on the reservation."

"On the ventilator" presents further difficulties because the preposition can be taken literally, leading the reader into an Alice-in-Wonderland state of mind where there is a crazy confusion over whether "on" might not really mean "under." I once got so lost in this Wonderland, while "on the ventilator" and in a hospital context, that I could not make sense of the German short story I was attempting to read. When the protagonist was described as being "unter dem Ventilator," the only image I could conjure up was one resembling the cartoons drawn by Audrey King. It took a strong dose of common sense, and a good look at the context, to figure out that "ventilator auf Deutsch" can mean ceiling fan and that the image intended more closely resembled the bar scene from *Casablanca* than a surrealistic ICU.

With "on the ventilator" relegated to hospital-speak, those wishing to speak seriously about long-term reliance on ventilators frequently turn to the term "ventilator dependent," despite the negative implications of the word "dependent." Admirably straightforward, this term has a place in contexts where the focus of discussion is on the fact of physical dependency. To avoid Alice's Wonderland, it helps to call a spade a spade, and when discussing physical dependency on ventilators, saying so without slipping into murky euphemisms helps to achieve clarity, which is of course the goal of informative, as opposed to persuasive, communication.

However, when the context is broadened to include a social environment, calling attention to this physical dependency is clearly undesirable, and "ventilator user," with its implication of control, is the term of choice. It may even, as has been noted elsewhere, perform the political function of empowering the user and enhancing the perception of independence, although one wonders how much power can be conferred by tinkering with word choice.

The chief advantage of "ventilator user" is that "use" is a common word capable of a wide variety of syntactical arrangements and of making the use of a ventilator sound as common and natural as the use of a toothbrush or a can opener. Not calling attention to itself, this unpretentious term is clearly user friendly.

Even so, as has been observed, "ventilator user," with its implication of choice, seems inappropriate

in a context focussing on children and infants. Certainly an infant of five months can hardly have enough autonomy to exercise choice and thus properly use anything. Substituting "assisted" for "user," however, does not wholly overcome this objection since the word "assisted" is most often used in context with an adult doing something complex enough to need assistance.

Further, the syntactical possibilities of "ventilator assisted" lead right into Alice's Wonderland by allowing the reader to ask just what exactly the ventilator is assisting the infant to do. If the answer is that the ventilator is assisting the infant to breathe, "ventilator dependent" would probably be a better choice because it is less ambiguous, and, in the context of infants and children who are commonly considered to be dependents anyway, "ventilator dependent" seems appropriate.

But there are undoubtedly other objections, and finding a perfect word suitable for all contexts is as difficult as finding the exit to Wonderland. Though one may hope to meet the main objections with carefully considered word choices and though one may hope to control the meaning of those choices with sharply focussed contexts, this control is as fragile as Humpty Dumpty, who said "in a rather scornful tone" just before falling, "When I use a word, ... it means just what I choose it to mean — neither more or less." To keep from falling, about all one can do is to understand the full meaning of the words one chooses and to match those words as closely and unambiguously to the truth as spelled out in the context.

ADDRESS: Karan McKibben, Ph.D., 800 Daffodil Dr.,
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Editor's Note: This is the fourth "Musings" column from Karan McKibben, respiratory polio survivor since age 8.

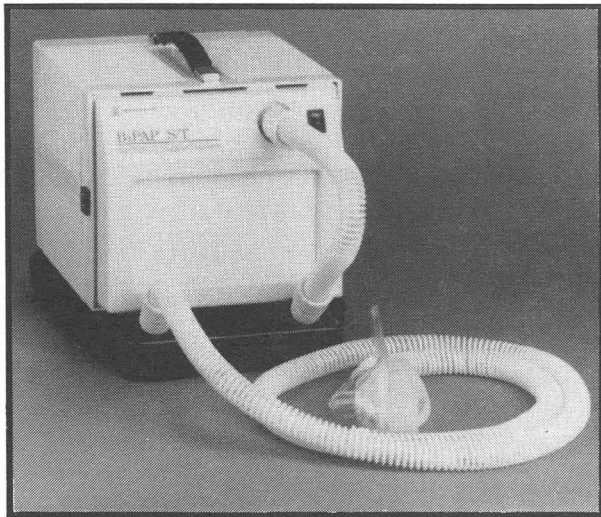
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SCI Quads May Need Night Ventilation

by John Quigley, Jr., D.Min.

I was paralyzed 26 years ago as the result of a diving accident, and now as a fortysomething C5-6 quad have partial use of my arms and wrists (no hands), but drive a van and lead a very active lifestyle.

I noticed sleep problems in 1985. I first attributed the gradual loss of stamina and energy and a general slowness in thought processes during the working day to normal aging. When I reported these signs to my internist he ordered a sleep study, which showed 12 episodes of sleep apnea per hour lasting from 20-55 seconds each. He suggested a tracheostomy, but thought this treatment too severe for my condition, and I agreed.

I had heard about CPAP (continuous positive airway pressure) through the G.I.N.I. conferences, but always had related it to polio. It suddenly dawned on me as I sat in on the 1989 G.I.N.I. conference that CPAP might help *me*. St. Louis pulmonologist Dr. Oscar Schwartz agreed. An in-home trial of CPAP confirmed its value. I rented a Thermodyne CPAP 7000 with standard nose mask and head straps and have been using it during the night for the last eight months.

My sleep is markedly better with no apneic episodes. There was an immediate return of stamina and energy after a full night's use. I now dream at night, which I had not done for years, indicating a deeper sleep than I had been getting before.

It was, and is, somewhat difficult to adapt to nighttime ventilation. It took three weeks to sleep a full night with the mask on. The major problem for me was claustrophobia. Another problem was learning to sleep with my mouth closed. After I learned this, the sensation that my mouth and nose were a wind tunnel was eliminated. A third problem, which remains, is the cold temperature of room air at night being pumped into my head and chilling me. I feel colder than my body actually is because I sense my head temperature acutely, but, of course, cannot sense the temperature of the rest of my body under the bedcovers. I placed a space heater in the vicinity to warm the ambient air, however, I understand that CPAP units with temperature and humidity regulators are being designed. The last problem is that the mask irritates one side of my nose which I am now treating with hydrocortisone cream.

Interpersonally, a ventilator adversely affects one's sense of comfortable intimacy with one's mate

in bed, but it is a manageable, yet frustrating, side effect.

I would strongly recommend that other SCI quads experiencing daytime drowsiness, energy loss, and/or morning "battle fatigue" have their sleep evaluated. Sleep apnea is a more common problem for those of us with limited or nonexistent respiratory musculature than we might expect. It is easy to overlook this problem when we don't seem to have any significant breathing problems during the day; we assume that we also don't have any problem breathing at night.

I would also advise a person to stick with CPAP during the initial adjustment period. Like everything else in life, we can and will adapt. It will be worth it in the long run. I now sleep soundly and without interruption throughout the night and awake refreshed.

ADDRESS: Jack Quigley, 9 Lenox Place, St. Louis, MO 63108.

Editor's Note: Jack Quigley is Minister, First Congregational Church of Webster Groves, and former President of the G.I.N.I. Board.

National Center for Home Mechanical Ventilation

Barry Make, M.D., of the National Jewish Center for Immunology and Respiratory Medicine, is Medical Director of a nonprofit research organization, the National Center for Home Mechanical Ventilation, dedicated to improving the safety and efficacy of positive pressure ventilators used in the home by way of tracheostomy or nasal mask. The Center's objectives are to develop a national database of positive pressure home ventilator users; collect information concerning suspected malfunctions or inappropriate application of equipment and supplies in the home; and develop improved methods of training individuals and health care providers.

Data will be collected through the national branches of LINCARE and Glasrock Home Health Care. Respiratory therapists working for these companies will submit data collection instruments to the Center for processing and computer storage. Karen Glenn, R.R.T., is data coordinator.

Operations are funded by ventilator manufacturers (Aequitron Medical, Inc.; Bear Medical

Systems; LIFECARE; Puritan-Bennett Corp.), home care vendors (Glasrock Home Health Care; LINCARE; The Pediatric Professionals, Inc.), and equipment suppliers and pharmaceutical companies (Baxter Healthcare Corp.; Cryogenic Associates; Hudson Oxygen; Instrumentation Industries, Inc.; Schering Laboratories; Siemens Life Support; SmithKline Beecham Pharmaceuticals).

ADDRESS: National Center for Home Mechanical Ventilation, 1400 Jackson St., J104, Denver CO 80206. 303/398-1949.



Home Ventilation in Germany

Edward A. (Tony) Oppenheimer, M.D., of Kaiser Permanente, Southern California, writes, "It was a pleasure to spend four weeks at the Chest Diseases Medical Center in Heidelberg, Germany: the Thoraxklinik der LVA Baden. This is an excellent 350-bed hospital and ambulatory care referral center. Dr. Matthais Wiebel in the Pulmonary Medicine Division is enthusiastic about rehabilitation and home use of mechanical ventilation, particularly with noninvasive approaches such as nasal positive ventilation using custom-fitted silicone masks similar to those developed by Dr. Dominique Robert at the Croix-Rousse Hospital in Lyon, France.

"The health insurance system supports the care and the equipment needed. Home health agencies to assist with followup care are generally not available, so Dr. Wiebel does his own followup at his patients' homes and at the Thoraxklinik. I was impressed by the careful discussion of medical consideration to allow patients to properly participate in decision-making."

ADDRESS: Dr. Matthais Wiebel, Thoraxklinik, Amalienstr. 5, D-6900 Heidelberg, Germany. Dr. E.A. Oppenheimer, Southern California Permanente Group, 4950 Sunset Blvd., Los Angeles, CA 90027.



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I.V.U.N. Potpourri ...

The National Association for Ventilator Dependent Individuals (NAVDI) held its first program on "The Faces of Ventilator Dependency" to address the need for health care service development on September 20 in Erie, Pennsylvania. For more information about the outcome of the meeting and NAVDI, contact Dan Dubowski or Kathy Ellis, NAVDI, 3607 Poplar St., P.O. Box 3666, Erie, PA 16508. 814/455-6171.



"Suffer Not the Children" is a 30-minute video examining the financial insensitivity of public policies to the catastrophic health needs of America's ten million chronically ill children. The documentary focusses on the heroic efforts of parents across the country as they struggle to bring their children home. Available from the Foundation for Hospice and Home Care for \$29.95 plus \$6.00 shipping and handling. Call Coleen Noland, 202/547-6586.

Bronchopulmonary Dysplasia: A Parent and Caregiver's Guide by Susan F. Delaney, A.A.S., R.R.T., and Claire Aloia, M.S., R.R.T., is a basic guide for those who have just brought a baby or child home. Charts, lists, photos, and sketches help make this a workable tool. Available for \$9.00 postpaid from Delclaire Books, 2520 E. Maple Terrace, Marcellus, NY 13108.



"Introduction to Noninvasive Ventilation" video by LIFECARE interviews prominent medical professionals discussing the benefits and limitations of noninvasive ventilatory techniques. The 25-minute VHS video is available for \$39.00 from any LIFECARE office. Call Jim Seeley, 303/666-9234.



Central Hypoventilation Syndrome Parent Support Network (formerly Ondine's Curse), 71 Maple St., Oneonta, NY 13820.

CALENDAR

◆ Pediatric Users Network

December 8, 5:00-7:30 P.M.
New Orleans Hilton

(during the annual meeting of the American Association of Respiratory Care). For more information, call Jan Nelson, Aequitron Medical, 800/824-7203, ext. 256.

◆ Pacific-Asia Conference on Pulmonary Rehabilitation and Long-Term Mechanical Ventilation

February 27-28, 1991
Pacific Beach Hotel,
Honolulu, Hawaii.

For registration information, contact Kris Hara, R.R.T., or Helen Ono, R.R.T., Kuakini Medical Center, Pulmonary Services, 347 N. Kuakini St., Honolulu, HI 96817. 808/547-9532.

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