

I.V.U.N. NEWS

International Ventilators Users Network

Spring 1991 ■ Volume 5, No. 1

Georgia Ventilator User Now Lives Independently

by Judith Fischer

In December 1990, Jenny Langley made her move — as Georgia's first quadriplegic ventilator user to pursue a self-managed, independent lifestyle — into a ranch-style home in Jonesboro.

"I hope to prove that anyone in my situation can live a normal life, instead of living by institutional rules and regulations," says Langley, who is 27. Langley has used a ventilator for the past three years because of an auto accident that left her quadriplegic. With the help of Shepherd Spinal Center in Atlanta, the country's largest spinal cord injury rehabilitation center, she hopes to show Georgia's elected officials that this living arrangement is more cost-effective and provides a better quality of life than institutionalization.

Money provided by Shepherd's Indigent Care Trust Fund (\$65,000) will enable Langley to manage her household and direct her own care in a rented home for one year. She will pay the bills and will interview, hire, and train her own attendants. So far, she is meeting her goal of staying within a budget of \$125 per day for all expenses. (Compare that cost with a typical daily nursing home cost of \$300-\$500.)

Jenny Langley's situation is not unique, but independent living options for people who use ventilators are non-existent in Georgia. The state's lack of suitable alternatives first received national attention when quadriplegic Larry McAfee petitioned the courts for the right to end his life.

More recently, Langley's family reached a point where they could no longer shoulder the financial and emotional stress of her 24-hour care. "My family's home was auctioned last July to cover unpaid debts," says Langley. "Medicaid benefits

covered such a small portion of my day-to-day expenses that my family was destroyed financially trying to provide for me. We're a perfect example of how the system didn't work, and I hope what we are doing now will make a difference."

Langley's history of living with a disability dates back to 1977, when she was paralyzed from the chest down in a diving accident. Then, in 1987 came the car accident, and Jenny Langley became a high level quadriplegic. Because her family's insurance coverage was exhausted from the first injury, the Langleys relied on Medicaid support after the second injury.



Jenny's Homecoming — local and national press, as well as Jenny's family, welcome Jenny to her new home in Jonesboro, Ga.

When she was admitted to Shepherd Spinal Center last summer for respiratory problems, Langley found herself with nowhere to go upon discharge. Officials at Shepherd began exploring her options, which were bleak, but familiar. Over the past two years, Shepherd had been forced to release nearly 20 patients to nursing homes — usually in other states. The inappropriateness of the situation is underscored by the fact that none of the people were sick; they just had nowhere else to go because Medicaid reimbursement did not provide for attendant care in the home.

During hearings for Georgia's Department of Medical Assistance 1992 budget, the Langleys

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Cost Comparison of Ventilator Care in Minnesota: Is Home Really Cheaper?

Frank J. Indihar, M.D., in a communication to the editor of *Chest*, January 1991, discussed monthly care costs for five longterm ventilator users in six different locations (one patient was in the ICU before moving to a respiratory care unit) in the metropolitan St. Paul/Minneapolis area.

Compare:

Intensive care unit	
(Bethesda Lutheran).....	\$82,643.70
Home Care A.....	\$34,665.00
Prolonged respiratory care unit	
(Bethesda Lutheran).....	\$26,964.30
Home Care B.....	\$25,870.50
Group Home.....	\$9,378.00
Home Care C.....	\$8,265.00

Home Care A costs included 24 hour RN-LPN, while Home Care B costs included 8 hour RN-LPN and 12-14 hour attendant care. The low cost of Home Care C included no costs for RN-LPN; care was provided by the family and 12-14 hour attendant care. The specialized respiratory care unit's lower cost can be attributed to the unique sharing of duties by nurses and respiratory therapists.

As Dr. Indihar concludes, "The cost of home care, when comparing equivalent personnel (a major determinant of cost), is not always particularly cost-effective when compared to other forms of institutional care. For certain types of patients, group homes may provide a cost-effective and humanizing source of care, although these patients must be carefully selected."

ADDRESS: Frank J. Indihar, M.D., Bethesda Lutheran Medical Center, c/o 710 Gallery Bldg., 17 West Exchange St., St Paul, MN 55102.

Who Pays for Ventilators for Polio Survivors?

Jim Seeley, Marketing Manager for LIFECARE, recently clarified the roles of the March of Dimes, private insurance, and Medicare/ Medicaid in paying for ventilators used by respiratory polio survivors.

Seeley writes, "The March of Dimes (MOD) assistance for polio survivors who use ventilators is not a 'well-guarded secret,' but apparently not well known. It is substantial and there are only a few requirements.

"First, the diagnosis on the prescription for ventilator equipment must mention polio. Second, MOD's assistance only covers ventilator equipment and accessories (humidifier, suction equipment, and hoses) obtained through LIFECARE. It does not cover other equipment that may be needed such as wheelchairs or hospital beds and it will not cover equipment obtained through other sources.

"If the ventilator user has no insurance and is not eligible for Medicare or Medicaid, MOD will pay for all the equipment. However, in this case, MOD will only approve the earlier types of equipment, such as blowers, Bantams, iron lungs, rocking beds, exsufflation belts, 170Cs, chest shells, pulmo-wraps, and PVVs. They will not pay for PLV-100s, PLV-102s, Nu-Mo suits, or Porta Lungs.

"If the ventilator user has insurance or is eligible for Medicare or Medicaid, the equipment must be billed to the insurance carrier, Medicare, or Medicaid first, and MOD will pay the 20% not covered. In this case, all types of ventilators are covered, including the PLV-100 and PLV-102. However, the ventilator user is responsible for any deductibles."

ADDRESS: Jim Seeley, Marketing Manager, LIFECARE, 655 Aspen Ridge Dr., Lafayette CO 80026. 303/666-9234.

International Ventilator Users Network (I.V.U.N.)

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

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Health Has No Frontiers

by Evelyne Valliere

(Translated from the French by Allen Goldberg, M.D.)

My name is Evelyne Valliere of Grenoble, France. I am 31 years old, I love life, and I have used mechanical ventilation at night with a nasal mask since 1986.

In 1972, I was 13 years old, and, like many young girls my age, I went to school and participated in sports such as skiing and speed skating. Once, because of a simple ski accident, I required X-rays which revealed some suspicious spots on my spine and ribs.

Very soon, these examinations led to further inconclusive diagnostic studies and cobalt therapy which had as a secondary effect necrosis of four dorsal vertebrae and reduced elasticity of my right lung. Only later was the true diagnosis learned — vertebral angioma — which would not have required such aggressive treatment.

For three years, in order to stabilize a progressive kyphoscoliosis caused by the deterioration of the vertebrae, I used a back-support orthopedic brace. It became evident that I needed a bone graft and, from January 1976 - December 1978, I lived in the Centre de Reeducation Fonctionnelle des Massues (Rehabilitation Center) in Lyon, France. There, after many prolonged treatments to lengthen my spine, I underwent five surgeries.

First, in April 1976, I had a spinal fusion with a Harrington rod implant, followed in May by an anterior bone graft. However, the strength of those procedures was insufficient. A repeat fusion was performed in June 1977, followed by another anterior graft. At this time, serious neurological difficulties appeared — spasticity/paraplegia — which necessitated an anterior vertebral release in December 1978.

I had nearly total recovery due to months of rehabilitation. As a result of the cobalt therapy and the subsequent chest wall deformity, my vital capacity, which had measured 1.8 liters in 1976, measured 0.75 liters after the last operation. I lost 12 kgms. (26.4 lbs.) and don't weigh more than 30 kgms. (66 lbs.).

Despite everything, from 1979-1985, I lived relatively well and overcame each of the difficulties that presented themselves to me, one after the other. I continued and completed my academic life and then worked, first as a preschool teacher, then in a bank. It was during this period (September 1983) that I discovered archery at a sports organization for people with a physical disability. I appreciated immediately the movement that gave me the sensation of breathing better.

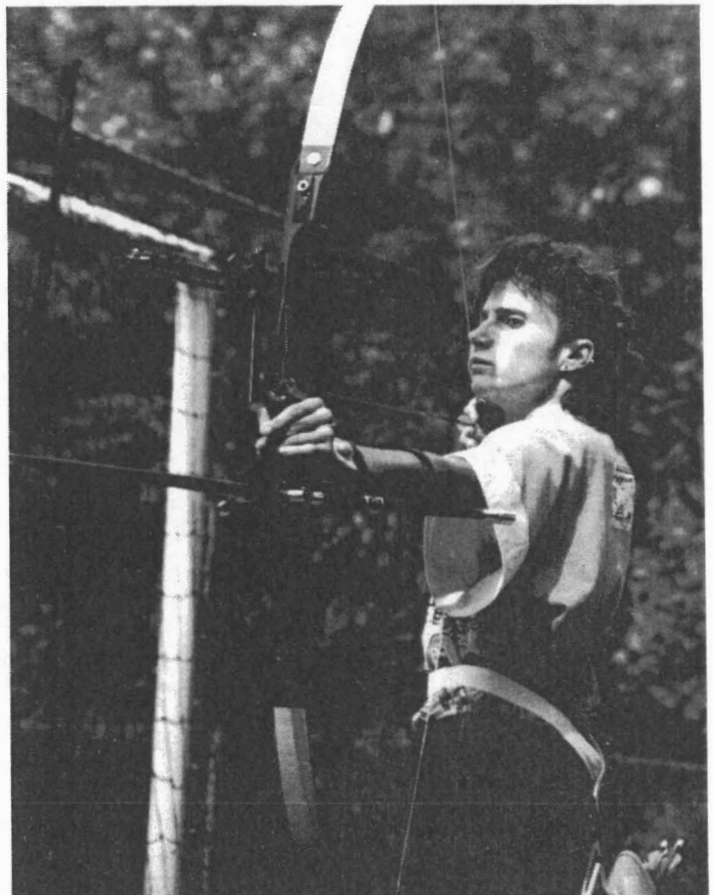
In September 1984, I participated in my first competition with a group of nondisabled archers in my town, and, in January 1985, at a first regional championship for people with disabilities.

In April 1985, one part of the Harrington rod came out of the vertebral body. A new operation was required to remove this material. My neurological troubles reappeared and my vital capacity fell to 0.5 liters. My life unfolded then like a slow motion movie, and became a trial for each moment — sleep difficulties, headaches, difficulty in moving about, in doing everyday tasks, in living ... very simply everything! There was no longer a question for me of archery.

I had to respond. In January 1986, I met Professor Dominique Robert for the first time at the Croix-Rousse Hospital in Lyon. The decision was hard to take, but I accepted adjustment to the Monnal D (ventilator) with nasal mask.

From that point on, all my life improved. I resumed my archery and my sporting performances became more and more satisfying. The ventilator and nasal mask gave me a new breath of life. I determined to organize myself in order to recover

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Georgia Ventilator User

(continued from page 1)

pleaded for help. Their pleas were successful — the 1992 budget includes a state appropriation of \$100,000, which will be matched with federal funds. This will be the seed money for an independent care program in Georgia.

Jenny Langley's new home is equipped with many sip and puff devices to enable her to turn on the lights or the television. Her sister, Sheryl Langley, and her sister's two daughters share the house with her. "Jenny's not sick, so she doesn't need a doctor," says her sister. "She just needs someone to help her get up and into her chair — things like that."

Larry McAfee, inspired by Langley's move, now lives in an independent care group home in Augusta, Georgia. "Anytime you can get away from an institutional setting, it's more stimulating. It allows you the freedom to live," says McAfee.

Jenny Langley always believed that she lived for a purpose, and now, she is wondering if that purpose isn't to convince the bureaucracy that living her own life in her own home is both possible and cost-effective.

ADDRESS: Jenny Langley, 2973 Drexel Lane, Jonesboro, GA 30236.



Jenny Langley

Georgia Statistics

- Medicaid program limits options available to people with disabilities who have exhausted their financial resources — the infamous "spend down syndrome." Only 4 percent of \$2.2 billion spent by the Department of Medical Assistance is spent on community health services — 34 percent is invested in nursing home care.
- Average per diem for nursing care is \$40.44, while only \$11.34 per day is invested in community health services.
- In 1989, there were five nursing home placements for every one person served by community care. It is estimated that nearly 1,050 people in nursing homes in Georgia are people with disabilities who are not sick but merely need attendant care.
- Ventilator users usually end up in state-supported facilities where cost of care is estimated at \$750 per day.
- When there is no option but to release a patient to a nursing home, hospitals like Shepherd Spinal Center have found that most nursing homes are reluctant to accept ventilator users. The person often ends up in a nursing home in another state (usually South Carolina or Florida) where that state's Medicaid program is forced to pay for nursing home care.

Statistics provided by Shepherd Spinal Center.

Apologies to S. Scott Cameron

S. Scott Cameron's story, "For the Shape I'm In, I'm in Pretty Good Shape," appeared in the Fall 1990 issue of I.V.U.N. News. The editor inaccurately and mistakenly led the reader to believe that Scott was in respiratory failure *before* he entered the hospital.

Cory Cameron, Scott's mother, writes, "Scott did not enter the hospital in respiratory failure. He had suffered episodes of respiratory complications at home, and his father and I had consulted Dr. Petty about anything that could be done to prevent respiratory failure and the circumstances that caused the deaths of his brothers at ages 19 and 20. The procedure explained to us was then presented to Scott and it was his ultimate decision to proceed. Thus the elective tracheostomy was performed and unfortunately the complications which followed necessitated the use of a ventilator very soon."

Mrs. Cameron concludes, "Several years ago someone asked Scott's father if he thought Scott was happy. His father replied, 'I think Scott is happy every morning when he wakes up and realizes he is still alive.' Without Scott's great desire and determination to stay alive, he most surely would have succumbed long ago."

The editor apologizes most sincerely to Scott, and is glad to learn that he has received many compliments on his article. Dr. Steven Ringel, of the Muscular Dystrophy Clinic at the University of Colorado Health Sciences Center, wrote to Scott, "You are quite right that the support of your parents, relatives, and friends make it all worthwhile — there's one other fantastic person involved — you!!"

I.V.U.N. Directory Update, Spring 1991

This directory update is to be used in conjunction with the directory published in I.V.U.N. News, Fall 1990, Vol. 4, No. 2.
Please send additions, deletions, and corrections to I.V.U.N., 4502 Maryland Ave., St. Louis MO 63108 USA.

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Deadline ...

for submission of articles, stories, information, etc.,
for the Fall 1991 issue of I.V.U.N. News
is August 15, 1991.

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

Complete Home Attendant Care ... Someday

by Ira E. Holland

Concepts of Independence, Inc., is a unique New York City-based, Medicaid-funded, home care program which initiated service in 1980. In this program the client is responsible for all aspects of case management, including the hiring, training, and supervising of home (personal care) attendants.

Currently, Concepts provides service to more than 300 self-directing individuals who wish to take an essential role in their plan of care. Of these 300 clients, approximately 30 use some form of ventilatory support and eight have tracheostomies.

Historically, there has been a complexity of problems regarding the provision of home care services for those of us who use ventilators. Most home care agencies do not wish to provide any level of service at all because of the perceived threat of liability and the concern regarding the ability to provide uninterrupted attendant care.

Unless the person is affiliated with Concepts, the provision of service to ventilator users has been uncertain, in which case the individual assumes responsibility for attendant care.

Those who live with a tracheostomy have another formidable obstacle because a home care attendant in the state of New York cannot perform suctioning of the tracheostomy. Rather the client must designate an informal caregiver to act as the one who will assume full responsibility for this task. People with tracheostomies have been put in the position of having to seek assistance from friends or family to cover what is otherwise an essential part of their personal care.

Dr. Augusta Alba, of Rusk Respiratory Rehabilita-

tion Center at Goldwater Memorial Hospital in New York, has been a long-time advocate of permitting a trained, unlicensed caregiver to perform suctioning. For 30 years, Goldwater Memorial Hospital has been training a group of nurse's aides in suctioning throughout the hospital. They are upgraded with the title of Med. Surg. Technician.

Dr. Alba, after meeting on a number of occasions with a group of clients at the Concepts office, decided to enlist the support of the American College of Chest Physicians (ACCP). Dr. Allen Goldberg of Chicago, also a longterm advocate of home attendants, presented the concerns of the New York group to the ACCP.

The accompanying letter in *Chest*, December 1990, clearly states that "The ACCP Respiratory Care Section promoted non-credentialed attendants as alternative caregivers for ventilator-assisted individuals including those with stable tracheostomies."

It is hoped that the publication of this letter and the support of the ACCP will ultimately result in legislation that will once and for all permit complete provision of services to all Concepts' clients, tracheostomy or not.

ADDRESS: Ira E. Holland, 540 Main St. (B432), Roosevelt Island, New York, NY 10044.

Ed. Note: As this article went to press, New York Senate Bill No. 475, which was introduced by Senator Michael Tully, Jr., calling for a demonstration project to expand the responsibilities of home care attendants to include suctioning, was stalled in committee, due in part to the severity of the budget crisis in the state.

Caring for Mechanically Ventilated Patients at Home

To the Editor:

People requiring prolonged home mechanical ventilation have utilized personal caregivers to augment self-care and family efforts since the poliomyelitis era. They can be used by the older child in the self-directing family, by the self-directing adult, and by the adult who in the opinion of the professional staff of a vendor agency can be safely cared for by personal caregivers with periodic nursing supervision. Models exist abroad,^{1,2} and in New York, where ventilator users recruit, hire, train, and manage such caregivers in a quality, cost-effective, client-maintained program.³ The personal caregiver is allowed to provide tracheostomy care, suction the tracheostomy, and check ventilator settings.

The ACCP Respiratory Care Section promoted non-credentialed attendants as alternative caregivers for ventilator-assisted individuals.⁴ The ACCP reviewed the positive 30-year experience of

Goldwater Memorial Hospital and Concepts of Independence.⁵ The ACCP is "highly supportive of the concept of Personal Care Attendants for supplementation of long-term home care for prolonged mechanical ventilator patients."⁶ They "can provide the means for chronic ventilator patients to have independent living and family centered care," and accomplish "a remarkable degree of cost savings at a time when we are looking for ways to bring down the costs of medical care."⁶ "Such attendants, properly trained, are safe and completely satisfactory."⁶

Allen I. Goldberg, M.D., F.C.C.P.,
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**Gazette International
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International Ventilator Users Network

SURVEY

The purpose of this survey is to provide I.V.U.N. useful information which will help us to better "network" ventilator users with each other.

Collecting this data will help I.V.U.N. identify specific network members so that I.V.U.N. may refer them to other network members with similar equipment and adaptations when problems arise or when new users need information and support.

Please assist us by completing the following questionnaire. Filling in your name and address is, of course, optional. If you wish to be part of an active network, completion of the personal information is encouraged.

Thank you for returning the completed survey by June 24, 1991.

Please return your completed questionnaire to:

**International Ventilator Users Network
c/o G.I.N.I.
4502 Maryland Avenue
St. Louis, MO 63108 U.S.A.**

10. Please identify the accessory equipment that you routinely use with your ventilator.

- | | | |
|---|---|--|
| <input type="checkbox"/> Reusable Circuit | <input type="checkbox"/> Reusable Exhalation Valve | <input type="checkbox"/> Lipseal |
| <input type="checkbox"/> Disposable Circuit | <input type="checkbox"/> Reusable Artificial Nose | <input type="checkbox"/> Suction Machine |
| <input type="checkbox"/> PEEP Valve | <input type="checkbox"/> Disposable Artificial Nose | <input type="checkbox"/> Blower |
| <input type="checkbox"/> Nasal Face Mask | <input type="checkbox"/> Bacteria Filter | |
| <input type="checkbox"/> Oxygen Tank | <input type="checkbox"/> Oxygen Enricher or Blender | |
| <input type="checkbox"/> O ₂ Adapter | <input type="checkbox"/> Oxygen Concentrator | |
| <input type="checkbox"/> Liquid Oxygen | <input type="checkbox"/> Portable Battery | |
| <input type="checkbox"/> Portable Battery Charger | <input type="checkbox"/> Power Generator | |

11. Have you invented or adapted any equipment or accessories that you routinely use in your own care?

- Yes No If yes, please describe: _____

12. Your primary ventilator is: Owned Leased

If leased, who pays the monthly lease?

- Self Medicare
 Insurance Company (Please name company _____)
 Other _____

If leased, who provides your ventilator:

- Home care company Hospital Other _____

If you own your ventilator, when you first acquired it, was it: New Used

How did you acquire it?

- Insurance company purchased outright Hospital loan closet
 Paid for out of personal funds Charitable donation
 Other _____

13. How often does your primary ventilator receive preventive maintenance which requires that you use a different ventilator?

- As-needed Once a year Twice a year It has never required this type of maintenance

14. Do you have a back-up ventilator? Yes No

If yes, is it the same as your primary ventilator? Yes No

If not the same, please identify type and/or brand of back-up: _____

Who pays for the back-up equipment?

- Self Medicare
 Insurance Company (Company name: _____) Other _____

If no, how far are you located from the nearest medical facility?

- < 15 minutes 15-30 minutes 30-60 minutes > 60 minutes

1. How long have you used a ventilator?

- <1 Year 1-5 Years 6-10 Years 11-20 Years
 21-25 Years 26-30 Years 31-35 Years 36-40 Years 40+ Years

2. How many hours a day do you typically use a mechanical ventilator?

- 24 Hours/Day 16-24 Hours/Day 8-16 Hours/Day
 4-8 Hours/Day Up to 4 Hours/Day _____ Hours using night ventilation

3. Do you practice glossopharyngeal breathing (GPB or frogbreathing)? Yes No

If yes, when do you use it _____

For how long? <10 minutes 10-30 minutes 31-60 minutes >60 minutes

4. If you were to lose power to your ventilator, how long could you sustain yourself without manual ventilation?

- <2 Minutes 2-5 Minutes 5-10 Minutes
 10-20 Minutes 20-40 Minutes 40-60 Minutes >60 Minutes

5. What type(s) of ventilator(s) do you currently use?

- Positive Pressure Negative Pressure Rocking Bed
 Nasal Mask Mouthpiece Chest Shell Pneumo-Belt
 Trach Intermittent mouth PP Pneumo-Wrap Iron Lung
 Porta Lung Other _____

6. If you identified above that you have a trach, is it: Cuffed Open Fenestrated

7. Do you use a speaking valve? Yes No If yes, please identify the brand _____

8. What brand(s) of ventilator(s) do you currently use?

- Aequitron Model _____ LifeCare Model _____ Puritan-Bennett Model _____
 Bear Model _____ Life Products Model _____ Respirationics Model _____
 Emerson Model _____ Monaghan Model _____ Thompson Model _____
 Other _____

9. Have you ever used a different ventilator? Yes No

If yes, please identify previous type and year changed.

- Positive Pressure Negative Pressure Rocking Bed
 Nasal Mask Mouthpiece Chest Shell Pneumo-Belt
 Trach Intermittent mouth PP Pneumo-Wrap Iron Lung
 Porta Lung Other _____

_____ Year Changed Reason for change: _____

15. Do you receive care from a nurse or respiratory therapist? Yes No

If yes, please identify which type of caregiver: Nurse Respiratory Therapist

How often: 24 Hours/Day 12-18 Hours/Day 8-12 Hours/Day
 Daily Check Weekly Check Bi-Monthly Check
 Monthly Check Other _____

16. How often do you receive a check-up from your physician?

Annually Monthly Twice a year As-needed Other _____

17. When was the last time you saw your physician regarding your respiratory status, e.g. vital capacity?

Month _____ Year _____

18. Your diagnosis: Spinal injury Muscular Dystrophy ALS Sleep Apnea

COPD Polio Other (Please identify) _____

19. Year your condition was diagnosed: _____

20. Would you join a ventilator user support group in your area? Yes No

Personal Data:

21. Your birth date: Month _____ Day _____ Year _____

22. Name: _____

23. Address: _____

24. City: _____

25. State: _____ Zip: _____

26. Country: _____ Postal Code: _____

27. Phone: (____) _____ - _____

28. Identify your occupation: _____

Please feel free to provide any additional data about yourself or your use of respiratory equipment that you think is appropriate. If the information is additional to a specific question from the survey, please identify that question with its appropriate item number.

THANK YOU FOR YOUR PARTICIPATION IN THIS SURVEY!

Musings: About a Fatal Cliché

by Karan McKibben, Ph.D.

Usually I do not object too much to clichés, regarding them as mostly embarrassing in their display of unexamined thinking and careless writing. There is one cliché, however, that I find not simply embarrassing but actually life-threatening.

This cliché is the one television presents with the familiar scene of a patient surrounded by various and sometimes irrelevant medical equipment. While the camera zooms into a closeup of a ventilator, someone voices the opinion that death is preferable to being hooked up to a machine.

If the show is a documentary, the speaker is usually an authoritative commentator, perhaps Dan Rather on "48 Hours," who defies challenge. If the show is a soap opera, the speaker is a convincing peripheral character whose emotional intensity defies all reason, at least while the program is on.

But when my remote control snaps off the television, I begin to think about how natural it is to use machines to make life worth living. In fact, I am as happy as a kid with a new toy whenever I discover a new device that works and gives me more control over daily life.

The ventilator I use is thus not a fate worse than death, but rather just another machine that makes it possible to use a PC to create masterful documents, or a remote TV control to capriciously flip through channels, or a motorized wheelchair to mechanically stroll through the magnificent gardens of the Huntington Library.

Indeed, all of us, disabled or not, are hopelessly dependent on machines. We cannot clean our clothes without a machine, or cook a dinner, or tell the time.

We can make neither music nor war without machines. Yet no Guns and Roses fan would refuse to go to a concert because the music is "heavy metallized" with loud sound machines. And General Schwarzkopf would never refuse to wage war because he must use technical wonders like Patriot missiles and bombs that are "smart."

To be sure, there are many people, especially environmentalists, who decry our dependency on technology and dream wistfully about a Romanticized state of nature, where machines are not necessary. But in a state of nature, as Hobbes said long ago, "The life of man is solitary, nasty, brutish, and short."

More recently anthropologists have pointed out that we are by nature toolmakers; by making tools and machines to help us survive and enrich our lives, we express our nature. Even the most avid environmentalists cannot sidestep our toolmaking

nature, for they conclude their legitimate complaints by advocating more technology, e.g., recycling technology, alternative energy sources, machines to make fake furs.

Since it is more natural for us to live with machines than without them, there must be some other, unspecified fear that makes a TV viewer accept so readily the cliché about death being preferable to life sustained by technology. Perhaps this fear is the one Dr. Frankenstein experiences in all the reworkings of Mary Shelley's story about a technological marvel taking on a life of his own and escaping human control.

Perhaps we are afraid that our machines will escape our control and wreak havoc not only on our environment but on our very humanity. Perhaps we are afraid that too much reliance on machines will somehow allow the uncompromising laws of science to tyrannize the human spirit. Perhaps, too, the fear is simply the fear of losing personal independence.

Whatever the cause of the whole nightmare, it can be dispelled by realizing that we are not simply toolmakers but also rational beings. By making rational choices about what serves our interests and what does not, we can indeed remain in control and maintain our self-determination.

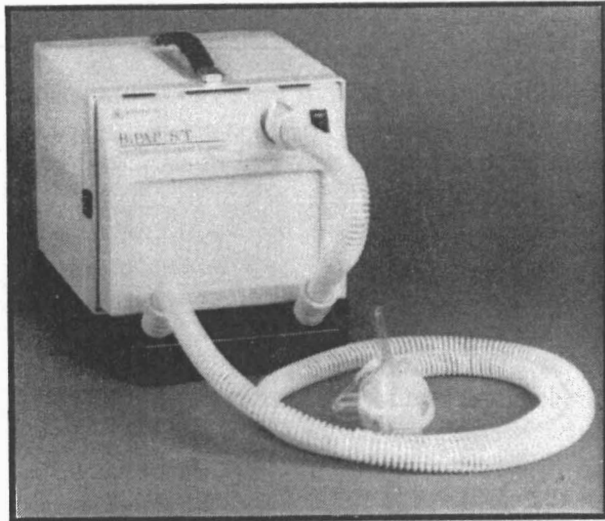
In the case of the cliché, the TV viewer should notice that the words are uttered by others, not by the patient, and that the camera is focussed on the machine, not on someone using a ventilator to live an active life. With the cliché, there is no rational decision-making, but simply emotional reaction to some unspecified fear.

Of course, the cliché owes its existence to the need for a dramatic sound bite to capsule the very serious issue of whether the life being sustained is actually worth sustaining, of whether there is enough human life to take control. But by focussing on the machine rather than the life, the cliché leads the viewer to a conclusion that belies our experience as born toolmakers and rational thinkers. Like all clichés and sound bites, this one passes on opinions and conclusions that are unexamined and likely to be based on false assumptions. When this cliché becomes part of someone's thinking about a real life decision, as I overheard in a hospital corridor, the cliché can be fatal.

ADDRESS: Karan McKibben, Ph.D., 800 Daffodil Dr.,
Riverside, CA 92507.

This is the fifth "Musings" column by Karan McKibben, respiratory polio survivor since age 8.

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Health Has No Frontiers

(continued from page 3)

my health as quickly as possible.

My ventilator and my archery became my two indispensable tools. Every time I was away for more than 24 hours, my ventilator followed me in its little valise. In April 1989, all my clinical parameters were clearly improved. My vital capacity was again returned to 0.75 liters ... 50% improvement.

Today, I am perfectly autonomous. I live alone in a two-room apartment in the same city as my parents. I have an automobile with special adaptations. I practice my profession three hours per week in a school where I teach archery to children. Part of my life is divided between medical care, sports, and daily life. I have a normal, active social life.

I am, however, obliged to save myself to the maximum extent and to protect my strength and my breath which I am so dependent on for fascinating activities. Thus I go out with or without my walking sticks or sometimes with a wheelchair depending on the efforts the distance requires. I use my automobile even for short distances. I often eat stretched out when I am alone, because it is in this position that I can best recuperate.

At archery, I shoot standing but my sporting friends bring along the arrows so that I can sit down and rest during these times. When I have a competition I avoid, for a week in advance, going out at night or activities that are too tiring. To succeed in



Evelyne Valliere at Regional Championship
in June 1989

archery, some sacrifices are necessary! During a competition that lasts all day, I require assisted ventilation in the middle of the day.

Financially I live modestly by means of an entitlement paid by the French government to persons with disabilities having few or no resources. This entitlement (a maximum of 2800 Fr per month = approximately \$545 USD) is calculated and prorated against income. I have a person to help me five hours per week with my housekeeping. Her salary is covered by an allotment from the state. Half the rent for my apartment is paid by a housing allotment, the other half by me.

For archery — a sport whose costs can be onerous — I have found sponsors. In 1989, Liquid Air, the manufacturer of the Monnal D ventilator, helped me cover my expenses. Without that help, it would be impossible to continue with the activity at this level.

When well managed, these different means of financial assistance enable me to live in the optimum way that I have chosen, very simply, but sanely.

Certainly some people think that this is nothing but functioning with assistance ... but today I know that my physical resistance has great limitations which would not permit me to conduct regular professional activity unless I respect my rhythm of life.

An accumulation of fatigue means for me hospitalization in Dr. Robert's service (the Service for Respiratory Insufficiency and Intensive Care) where I am regularly followed. The cost of this service represents the equivalent of the financial assistance from the government given to me for one month! In addition to Dr. Robert, I am followed at the Massues Center for orthopedic problems, and by a general practitioner, a physical therapist, and a respiratory therapist in Grenoble. I recently met, through one of the therapists, a physician who is looking for ways to better manage the interaction between breathing, nutrition, and efforts to obtain the best possible ways to live. I am very interested in how this will unfold, and I am trying all the steps of his approach with enthusiasm.

It was by chance that I discovered archery, a discipline that suddenly absorbed me. It is a sport in which respiration and its control represents part of the technique and aids in the performance. When I pull the bow, I get the impression that I breathe better.

I am currently a member of both the local sports club for people with disabilities and the club for nondisabled archers. I have been French national champion three times from 1987-1988, and currently am undergoing extensive training for the

(continued on page 14)

A Ventilator Assisted Child Becomes An Adult: What Then?

by Jerry Daniel

A child who uses a portable ventilator usually receives the best care from a devoted mother or father, or both. A stable, clean environment is set up in the home, and the parents do quite well in keeping their child free of infection and out of the hospital.

But is any change called for in living arrangements when that child reaches the late teens or early twenties? It depends, of course, upon the individuals involved. The matter should be discussed without offending the parents who have made the sacrifices for their son or daughter. If it is suitable for everyone involved for the child to stay in the parents' home, the situation should be evaluated from time to time.

As the parents age, the physical requirements for caring for the son or daughter can cause both emotional and physical stress in the parents. The parents' needs for their retirement years are just as important and valid as those of the young adult. Perhaps home attendant care is needed or perhaps the now grown-up child should consider going out on his or her own, either into a group home or into an independent setting.

When I was 21, I was using a ventilator only during the night. I had a car and was preparing to enter the working world. I didn't know if a person with a trach would be accepted in industry. I knew there would be days on the job when bronchial congestion would be a problem and I would not be able to use a suction machine or lie down for postural drainage.

After years of good family life, Mom wasn't there with the family dinner on Sunday. She was off playing golf with Dad and having dinner at the club with friends. That was okay, but when my parents sold our home and got an upstairs apartment shortly after I moved out, I almost felt that they were trying to cut out on me. I knew I could move back with them, but I was determined not to. Some of my friends who are also ventilator users had similar experiences, separating themselves from parents and trying to get into the working world.

Many young people who use ventilators and require full-time attendants have gone out on their own, but it takes a lot of support from the family and medical professionals to make it work, and good counseling on household management, finances, and hiring and firing attendants. Usually, it is the young person's compelling need to get into

an independent lifestyle, even if it temporarily upsets a devoted mother or father.

How well the young adult handles the challenges of ventilator life can determine whether he or she will make it on the outside. There is the challenge of keeping the ventilator equipment and accessories running smoothly. There is the challenge of maintaining good health and watching out for respiratory infections that could lead to hospitalization. There is the challenge of managing when an attendant does not show up.

The parents who have provided so much care and nurturing can help out in emergencies. They can bring over a meal, shop, and take over some care in a rough period. But an independent lifestyle for the young person often provides a chance for the parents and that person to enjoy a better, more equal relationship. Even though the ventilator user faces many obstacles, the family will respect him or her for the steadfast determination to make it on the outside. Each of us deserves a chance to be all that we can be.

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

Health Has No Frontiers *(continued from page 13)*

next Olympic Games. I can always dream ...

A trainer improves my archery technique two hours per week, and a sophrologue helps me to acquire better mental concentration. I use this concentration to better live with difficult limitations due to respiratory insufficiency.

My desire to succeed in this discipline has motivated me to follow seriously three weekly periods of physical therapy, 10 hours of nocturnal ventilation each night, and to accept to wear a rigid corset permanently.

Archery represents for me how I face my disability, which loses importance for both me and others. I am always surprised to see so many persons with respiratory disabilities who do not take part in sports. Sports *is* possible for them.

I hope to have made my contribution by this effort of self-reflection and by describing the use of these new techniques that permit more to move back as much as possible the physical limits of those who have respiratory insufficiency. I have great faith!

ADDRESS: Evelyne Valliere, "Le Prisme," 26 rue Emile Romanet, 38100 Grenoble, France.

Jerry Daniel, respiratory polio survivor since 1948, is a home ventilator equipment repair genius, especially for Aequitron's LP-3 and LP-4.



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Bill Tainter

Ventilator User to Head California Department of Rehabilitation

Bill Tainter, Executive Director of the Community Service Center for the Disabled, an independent living center in San Diego, was appointed by Governor Pete Wilson on April 4, 1991, to head California's Department of Rehabilitation. Tainter, 48, who contracted polio as a teenager, can walk, but has little use of his arms and uses trach positive pressure ventilation.

Tainter, who takes over the department (with a \$255 million budget) on May 1, is the second ventilator user to head the department — the first was Ed Roberts, another respiratory polio survivor.

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

S.K.I.P. Camp for families with technology assisted children is scheduled for August 18-23, 1991 in Minnetonka, Minnesota. The week is free to families and includes a small travelling stipend. The all-volunteer staff provides round the clock nursing care, respiratory therapists, and physicians. A non-medical staff is on hand to babysit younger siblings and help with the activities. Space is limited to 20 families sleeping over and 10 families who are day campers. Volunteers are needed! Families should apply by May 1 to Barbara Donaghy, SKIP Camp Family Retreat, 11208 Minnetonka Mills Rd., Minnetonka, MN 55343, 612/935-5581.

Directory of Sources for Ventilator Face Masks, compiled by Bud Blitzer for International Ventilator Users Network (I.V.U.N.) and Gazette International Networking Institute (G.I.N.I.), is hot off the press. The 16-page directory is available for \$2.50 postpaid. Please send a check (no cash) made out to I.V.U.N., 4502 Maryland Ave., St. Louis, MO 63108. Bud wants to know of other sources to be listed in future updates. Write Bud Blitzer, 400 S. Saltair, Los Angeles, CA 90049. Thanks, Bud!

CALENDAR

- ◆ **Beyond the ICU III: Perspectives on Ventilation**, April 19, 1991. Ramada Inn 400/401, Toronto Canada. Sponsored by the Committee for Independence in Living and Breathing, the Canadian Paraplegic Association. Call Steve McPherson, 416/241-8882.
- ◆ **Pediatric Users Network Meeting**, April 24, 1991. Hyatt Regency Hotel, Cincinnati, Ohio. Call Jan Nelson, Aequitron Medical, 800/824-7203, ext. 256.
- ◆ **C.S.R.T. Forum 1991: LP-6 Users Meeting**, June 14, 1991, 2:30 PM-5:00 PM. Holiday Inn Downtown, Winnipeg, Manitoba. Call Jan Nelson, Aequitron Medical, 800/824-7203, ext. 256.