

DEMANDS OF CAREGIVING FOR HOME-BASED VENTILATOR-ASSISTED INDIVIDUALS: A PRELIMINARY REPORT

by Mary Ann Sevick, ScD, RN

Recently, we conducted a nationwide survey of caregivers of home-based ventilator-assisted individuals (VAIs), regarding the nature of their caregiving activities, the impact of caregiving on their lives, and the indirect economic burdens associated with this effort. We included caregivers of VAIs who were clients of Homedco Inc., Abbey Home Health Care, Lincare Inc., as well as caregivers of members of the International Ventilator Users Network (IVUN). A full report regarding the results of this study is in preparation. This article presents preliminary findings from data obtained from caregivers of IVUN members.

Survey packets were mailed to the primary family caregivers of 142 IVUN members, 38 (26.8%) were returned. The packets contained instruments measuring the degree of assistance needed by the VAI, formal and informal supports/services required to maintain the VAI at home, and impact of caregiving responsibilities on the primary family caregiver of the VAI. Participants were paid \$5.00 for the return of a completed questionnaire.

The typical caregiver participating in this study was a relatively well-educated, white, female, middle-aged spouse/partner or parent of the VAI. The majority of VAIs for whom they cared (n=32 or 84.2%) had a neuromuscular disease such as polio or muscular dystrophy. Three (7.9%) had a spinal cord injury or disease and 2 (5.3%) had a congenital malformation resulting in the need for respiratory support. We were unable to determine the reason for ventilator dependence for one VAI.

Functional dependence of the VAI and assistance provided by the caregiver were explored using a modified Katz Index of Independence in Activities of Daily Living.¹ This instrument was originally developed to assess the functional independence of the elderly, including meal preparation, eating, bathing, dressing, ambulation, toileting, laundry, managing money, housekeeping, and transportation. It was modified by the investigators to, additionally, reflect self-care activities specific to ventilator-dependency including tracheostomy care, suctioning, and ventilator maintenance. Of the 16 caregivers from whom we have complete data, 5 (31.3%) indicated that the VAIs for whom they cared were completely dependent in all functional domains. Items on the Katz were zero-adjusted and summed to yield a score with 39 possible points, with higher scores indicating a

higher degree of independence. For these 16 cases, the average score was only 6.6.

Caregivers indicated that they had been caring for their family member an average of 260 months and devoted an average of 7.6 hours each day to their relative. We asked caregivers about the amount of leisure time they currently had each day, as well as daily leisure prior to becoming a caregiver. Respondents reported a current daily average of 4.4 hours of leisure, with an average loss of 3.8 hours of daily leisure since becoming a caregiver.

We asked caregivers to estimate monthly out-of-pocket expenses related to the health care needs of their family member. They reported spending an average of \$350 per month for unreimbursed health care expenses. Twenty-one respondents indicated that they had made major one-time purchases/home modifications to accommodate their family member's return home, including building ramps, electrical wiring, widening doors, van purchases, hospital beds, ventilators, suction machines, bathroom remodeling, elevators, oxygen systems, bathtubs, wheelchairs, and alarm systems. Respondents reported an average total charge of \$8,182. The average out-of-pocket amount paid for these items was \$7,485. Respondents estimated that home ventilator care

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HOME MECHANICAL VENTILATION: OBSTACLES TO LIVING AT HOME

Presented at G.I.N.I.'s Sixth International Post-Polio & Independent Living Conference
June 16-19, 1994, St. Louis, Missouri

by E.A. Oppenheimer, MD

I shall focus on seven critical points in the process which are frequent obstacles to living at home. The discussion should start at a time **before** mechanical ventilation is actually necessary for life support.

People with conditions that may lead to chronic respiratory failure and death unless longterm mechanical ventilation is used are mainly people with progressive neuromuscular disease, kyphoscoliosis, and those with progressive chronic pulmonary diseases. This is the "at risk" group.

People at risk of chronic respiratory failure and death unless longterm mechanical ventilation is used need careful evaluation and counseling by a physician experienced with longterm care and home mechanical ventilation (HMV). Whenever the term "physician" is used here, it refers to a team approach with other professionals including a social worker, respiratory therapist, physical and occupation therapist, etc. This evaluation and counseling usually requires a number of visits, and may need to include family members. Whenever HMV should seriously be considered, peer counseling and networking is advised. The **first** critical point is this careful evaluation and counseling, and it is often lacking.

If the person at risk is appropriate for longterm HMV after evaluation by the physician, and if the person is seriously interested, then the next step is to evaluate the resources to see if this option could be worked out in terms of funding and personal caregiver assistance. This is the **second** critical point: responsible advance planning. It often does not occur.

When the individual and family and physician agree on longterm HMV, if and when it becomes necessary, and if resources are available making it feasible, then noninvasive mechanical ventilation (NIV) should be considered whenever possible. A trial using NIV should be considered before ventilator assistance becomes necessary for life support. This provides the individual and family with hands-on experience, prepares them, and assists with decision-making. This is the **third** critical point, but due to lack of planning and experience, it often does not occur.

In contrast, most people who use longterm HMV in the United States have had an unexpected (unplanned) medical emergency, such as respiratory failure - often with infection, requiring hospital mechanical ventilation and intensive

care. Most hospital emergency areas start mechanical ventilation by intubation without trying NIV. When the individual cannot be weaned in the ICU, a tracheostomy is usually performed without considering NIV. This is the **fourth** critical point: tracheostomy is often used when NIV might have worked as well or better. The consequence is mechanical ventilation that is more complicated, has more risk, and involves greater costs. Most people prefer NIV to tracheostomy if they have a choice, however, in some cases tracheostomy is needed and appropriate.

During the hospital stay, the individual and family should learn to do all the needed care, including care related to the ventilator and other equipment. A team approach is needed for hospital discharge preparation, and familiarity with HMV. This is the **fifth** critical point: many hospitals do not have experience with HMV. The result may be a long hospital stay, transfer to a longterm care institution, or discharge home with inadequate training and arrangements. Most community hospitals can do this properly if they have a few key experienced professional staff members, including an experienced pulmonary physician.

The first six to twelve months of HMV usually require professional assistance to help coordinate care, solve problems, and monitor the home care, and to help with the transition to independence. The home care medical equipment company also needs to be well-versed in HMV. A seasoned home care professional team includes a physician, home health nurse, social worker, and respiratory therapist. This is the **sixth** critical point: home follow-up support often is inadequate. As time passes, the individual and the family should learn the care process and care coordination, and become increasingly self-sufficient. If the person is not very disabled in other respects, the major cost is for equipment, which can usually be worked out.

The **seventh** critical point occurs with the more severely disabled ventilator user who needs help with all aspects of personal care, and may need the ventilator for 20-24 hours per day. In this situation, the ventilator user needs someone else to help, because the family often cannot provide round the clock care. It is often difficult to find community support for personal assistance services to help with activities of daily living as well as the medical aspects of care. (Related issues include support for sophisticated communication

devices, mobility aids and equipment, transportation, and respite.) If the individual hires someone to assist as a personal attendant, he or she may pay \$6-8 per hour. However, if this care is provided by a practical nurse through a private duty agency, it may cost \$18-20 per hour. When 10-16 hours are required daily, the logistics are difficult, and a health plan or insurer often finds institutional placement more cost-effective.

The resources to support paid personal assistance in the home are a continuing challenge at the interface of medical care, community social services, and personal responsibility. The issue is further complicated by the controversy as to whether the care should be provided by personal assistance services or a licensed health care professional. Caregiver assistance may be the most difficult problem to solve. We hope there will be changes in health care in the United States resulting in better support for community-based longterm care.

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had resulted in an average increase in utility (gas, electric, water) costs of \$55 per month.

Twenty-seven (71.1%) caregivers indicated that they were employed at the time of the survey. Nine (23.7%) indicated that they had altered their employment to accommodate caregiving requirements, resulting in an average loss of earning of \$936 per month. Caregivers were asked what they would be willing to pay for a service that would relieve them of caregiving responsibility. Ten caregivers did not respond to this item. Of the 28 who did respond, the average amount they would be willing to pay per day was \$44. Fourteen (50%) caregivers said that they would not pay any amount for such a service.

Although we are not able to provide the data with this preliminary report, IVUN members appear to be more functionally independent and require less assistance than their counterparts surveyed through the home health care agencies mentioned above. Nevertheless, our study findings indicate that the average IVUN VAI has a moderate degree of functional dependence, and requires a moderate amount of assistance with activities of daily living. Caregivers devote a significant portion of their day to caring for their family member. For some, employment is compromised and wages are lost. Despite the personal cost to family caregivers, many respondents are

unwilling to pay anything for relief of caregiving responsibilities. Our previous research has demonstrated that caregivers do not perceive this situation to be a negative one.²

Because a sample of convenience was used and the non-response rate was high, caution must be used in drawing any firm conclusions from this study. However, the study does provide a basis for examining the premise that home care is a less expensive alternative than inpatient care for some VAIs. Although home care is the best and most logical place for many VAIs, existing studies of the cost of home care and reimbursement policies do not take into account the full range of costs that are "paid" by the family. These include decreased wages, extensive caregiving responsibility, unreimbursed health care and other expenses, and stress.

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This study was funded by the Agency for Health Care Policy and Research, and the Central Research Development Fund of the University of Pittsburgh.

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

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

Issued in the Spring and Fall

ISSN#1066-534X

Editor:

Judith Raymond Fischer

Design:

Sheryl Prater, Prater Graphics

Publisher:

Gazette International Networking Institute (G.I.N.I.)
Joan L. Headley, Executive Director
5100 Oakland Avenue, #206
St. Louis, MO 63110-1406 U.S.A.
314/534-0475 • 314/534-5070 Fax

Annual Subscription:

U.S.A.: \$8 for ventilator users; \$20 for others

Surface Mail: \$10 USD per year for ventilator users;
\$22 USD for others.

Air Mail: \$12 USD per year for ventilator users; \$24 USD for others.

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NONINVASIVE VS. INVASIVE VENTILATION

I.V.U.N. Readers React ...

From Susan Ray, "I see in the Spring issue of *I.V.U.N. News* that the old argument between ventilation by tracheostomy or 'noninvasive' means goes on. Everyone ought to use what suits them best, of course. But noninvasive ventilation has worked well for me for the past 42 years.

"I cannot take even one adequate breath with my diaphragm. Within a year of contracting polio at age 4, I spontaneously learned to do glossopharyngeal breathing (frogbreathing). I can do it for at least three hours, and probably could for some time longer if necessary. I have spent every night of the past 42 years in the iron lung. I have home-made ones for both home and travel. I do hope to soon try a nasal mask for sleeping; I've long dreamed of having such a thing, especially for trips.

"For day-time respiratory assistance I used a chest shell during my childhood. The doctors always fussed at me for frogbreathing along with it until they finally realized — or admitted — that it did not ventilate me adequately. By the time I was 13, it was threatening my breathing capacity by stretching my rib cage. Fortunately, mouth positive pressure had been developed by then. I was very skeptical at first, but adapted to it within a day. I have used it almost every day for 33 years.

"I do not have many respiratory infections, but during some colds and bouts with flu I have had to remain in the iron lung day and night for its assistance in helping me cough. I can sometimes clear congestion just with increased inspiration on my positive pressure unit plus a manual push against my diaphragm and/or postural drainage.

"Since I never had difficulty swallowing, my doctors never performed a tracheostomy on me, for which I have always been grateful. I think it is barbaric for doctors to assume tracheostomy is the method of first choice. Have the experiences of many of us polio survivors been for naught?"

ADDRESS: Susan Ray, 3110 Cavu, Georgetown TX 78628.

From Richard Daggett, "I contracted polio in 1953. Within 24 hours of entering the hospital I was given a tracheostomy and placed in a tank respirator. I could not move, swallow, or breathe. After about six weeks, the ability to swallow returned. After about four months, I graduated from the tank to a hospital bed, using a Monaghan ventilator with a cuirass. Ten months after onset I was free of any ventilator, my tra-

cheostomy was closed, and I was even walking short distances.

"For the next eight years I used no mechanical ventilator, but then my CO₂ began to rise slightly, and I used a Thompson Zephyr for chest stretching and cough augmentation. A few years later I returned to using a Monaghan and cuirass at night. My vital capacity was about 1000 ml and my CO₂ stabilized.

"During the ensuing years, I functioned very well and continued an active lifestyle, but two problems bothered me on occasion. The first was any severe respiratory infection. Although I was no more susceptible than the next person, I had a hard time if I had heavy, excessive secretions. I had a good cough on my own, and even better when I used the Thompson Zephyr, but heavy secretions made it difficult to inhale after each cough. At times it felt like I was choking on my own mucus, especially when the secretions were first breaking up.

"The second problem was with the ordinary throat tickle. If left unattended this would cause portions of my upper airway to constrict. Inhaling after a severe episode would be very difficult. I learned to keep mentholated lozenges with me at all times. At home I could alleviate the problem with a few swallows of water or other liquid. This was usually just an inconvenience, but several times it posed a very real danger.

"In 1984 I experienced a sharp drop in my pulmonary capacity. My vital capacity went from about 1000 ml to about 850 ml, and has continued to decline (my most recent reading was about 700 ml), no doubt due to the late effects of polio. Using the cuirass at night and the Zephyr during part of the day was no longer adequate. My CO₂ rose dramatically and my blood oxygen level fell to a dangerous low. After trying several noninvasive mouthpiece/nasal options with little success, I made the decision to have another tracheostomy. It was my decision, and I have no regrets.

"My upper extremity strength is limited, and I could never manage to put on or remove the cuirass by myself, nor the mouthpiece/nasal apparatus with its many straps and snaps. Using trach positive pressure, I can connect and disconnect the ventilator, and get in and out of bed by myself. I am better ventilated, and although I still get about the same number of colds, managing them is easier. I never worry about tickles or choking now.

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FROM TRACH-FREE TO TRACHED TO TRACH-FREE AGAIN

by Nancy Quinn

After returning from my honeymoon in September 1952, and not feeling well for several days, a diagnosis of poliomyelitis was finally made. I began a 14-month hospitalization at Haynes Memorial Hospital in Boston, embarking on a new way of life, far from what my husband and I had planned. Soon after hospitalization, I was placed in an Emerson iron lung, totally paralyzed. The usual forms of treatment were initiated: hot packs, physical therapy, and eventually weaning from the iron lung.

In January 1953, a rocking bed was introduced into the therapy program. For the next few months, I alternated between the lung and the rocking bed. Eventually I adjusted to sleeping on the rocking bed. In August 1953, my doctor said if I could sleep two months without the rocking bed, I could go home. To achieve this, the dip of the bed was gradually reduced, and by September, the bed was turned off completely. The weekend after Thanksgiving 1953, I was able to go home, free of any respiratory assistance.

I was admitted to Warm Springs for intensive rehabilitation in the spring of 1955. During this time, physical therapy helped me strengthen the partial use of my right arm and hand, and I learned glossopharyngeal breathing (frogbreathing). My vital capacity at that time was between 600-700 ml, and I began using a cuirass and

Monaghan ventilator for one hour each day. I left Warm Springs at the end of 1955.

During the next two years, I experienced episodes of CO₂ build-up. I was hospitalized and used an iron lung. After the second experience, my physician recommended using a cuirass for sleeping and resting. No serious illness occurred until 1960, when kidney stones became trouble-

During the recent G.I.N.I. conference in St. Louis, there were repeated questions from the audience about how not to wind up in the hospital with a trach. Dr. Tony Oppenheimer responded, "It's not a bad idea to stay alive. If you are in an emergency center where they know how to keep you alive, but do not use your preferred way of doing that, take life. You can always negotiate going to noninvasive later ... An endotracheal tube or even a tracheostomy tube can be taken out. You can make a transition to noninvasive. It is maybe not ideal, but we are talking about the ideal and we are not there yet. It is not such a terrible thing — staying alive and getting the opportunity then to negotiate."

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"There are negative aspects of course. I must clean the trach site daily. I need to be suctioned occasionally. I no longer can wear a tie, but I remain very active and have never felt shackled by my tracheostomy.

"The decision about tracheostomy is not an easy one. A trach is not for everyone. But for me and for a quite a number of others, it was the right decision. If you are experiencing sharply reduced pulmonary capacity, and are facing the possibility of a tracheostomy or other ventilator option, you should talk to your pulmonary specialist, but also to someone who has gone through this decision-making process. Other ventilator users will never be able to make the decision for you, but they can give you important insights — insights that only a ventilator user can offer."

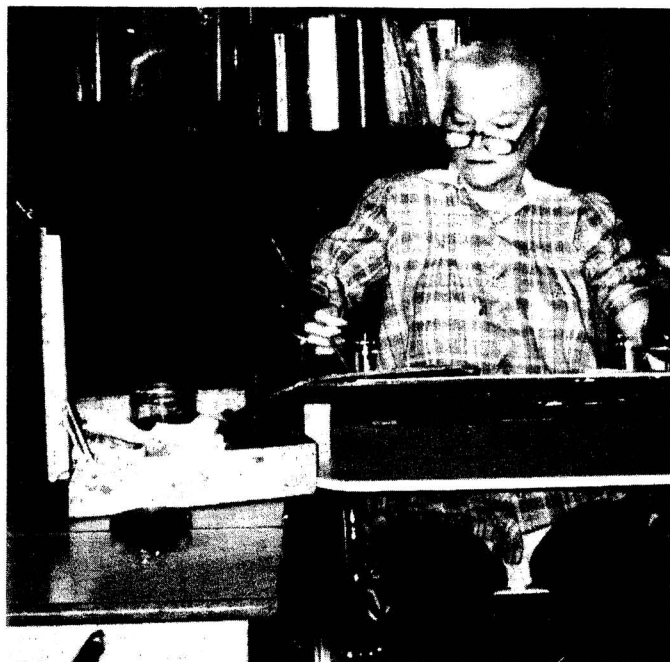
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some and had to be surgically removed. An iron lung was used for post-operative recovery, and after three weeks, my incision had healed enough to return to the cuirass. I also started using a blower to help keep the diaphragm stretched and functional.

In 1984, I began to experience extreme fatigue. My general practitioner suggested a consultation with Dr. Neil Feldman, a local pulmonary specialist. At this time, I switched to a larger cuirass, and at night the negative pressure was increased and the rate was decreased. This seemed to solve the problem until September 1987, when I was hospitalized with pericarditis. Because of the intense pain, I could not tolerate the cuirass, and CPAP via a nasal mask with a PLV-100 ventilator was introduced. Being a little claustrophobic, this was a difficult adjustment. However, sleeping was more restful, and after recovering from the pericarditis, CPAP became my permanent sleeping device.

In February 1990, bladder cancer required hospitalization for laser surgery. After much discussion about anesthesia, the physicians decided to

use an epidural. CPAP plus oxygen was used during the one and one-half hour surgical procedure. My attendant was allowed into surgery to set up and operate the CPAP. For the next three years, several additional laser procedures were required to control excessive bleeding and more tumors, but in January 1994, my urologist decided the bladder would have to come out or the cancer would spread. Since this was a four to five hour procedure that included a hysterectomy and the



Nancy Quinn painting

creation of an ileal conduit, my medical team felt a tracheostomy was necessary. After 43 days in CICU, I returned home with a urostomy appliance, the trach still in place.

I was extremely disappointed, discouraged, and depressed that the trach could not come out; I could not speak. While at home, I attempted using the Passy-Muir Speaking Valve, but was not successful, thus increasing my frustration and depression. The trach care and constant suctioning, sometimes 12-15 times per day, overwhelmed me. Still Dr. Feldman maintained his position, saying I would live longer with the trach than without it. I thought about his words for several weeks and finally realized he was not saying I could not live without it, only that I could live longer with it. I felt the quality of my life, no matter how short, was much more important than a long life of being miserable. I began to research the pros, cons, and alternatives to tracheostomies.

I do not remember why I started taking the inner cannula out during my bath and exercise periods, however, it seemed much easier to breathe, which surprised me. The secretions seemed to be my major problem. Since the trach

was causing the secretions, according to popular medical literature, it seemed logical to me that if it were removed, the secretions would no longer be a problem.

I wrote to Dr. Feldman, pleading that we discuss the possibility of removing the trach. To his credit, he agreed, and on June 13, 1994, I was again hospitalized in the CICU for the decannulization process. But my blood gases were too low. These finally stabilized, and on June 22, after applying a nasal cannula for oxygen and suctioning once more, Dr. Feldman painlessly extracted the trach. A gauze was placed over the stoma and my old cuirass put back on. My voice started to get stronger almost immediately. CPAP was again started during the night. Blood gases remained steady. During the next few days, I used either the cuirass or the blower, and sometimes nothing. I found I could eat and drink quite comfortably, and it was wonderful to be able to speak again.

Fortunately, the cuirass did not seem to compromise the efficiency of the urostomy appliance. In an effort to bring up secretions on my own, rather than be suctioned, I alternated between frogbreathing and the blower, with manual assistance. The stoma closed completely within a month, and so far there have been no further complications.

In retrospect, the tracheostomy, though necessary at the time, was a nightmare to me, even to the point where death seemed preferable. I realize many people manage well with their trachs, but it was not for me. I would advise anyone facing surgery to be prepared and to have a competent respiratory physician and a good respiratory team who know neuromuscular disease. Asking the right questions and understanding the answers encourages a good team effort and confidence in what is going to occur.

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for submission of articles, stories,
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issue of *I.V.U.N. News* is
February 28, 1995.

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FORUM FOR VENTILATOR USERS

*Transcripts from a panel during
G.I.N.I.'s Sixth International Post-Polio & Independent Living Conference
June 16-19, 1994, St. Louis, Missouri*

❖ IMPROVING COUGH AND DECREASING INFECTION

SUSAN SORTOR LEGER, RRT, LYON, FRANCE

Coughing is a protective mechanism to help clean the lungs. An effective cough is strong enough to carry secretions or foreign objects or particles from the lungs to the upper airway. Lung irritations include smoking, aspiration, allergies, air pollution, and viral or bacterial infections. The latter will cause an increase in the amount of secretions as the secretions try to cleanse the lungs. If there is an increase in secretion productions and one can't cough effectively, mucus stagnation occurs. If mucus sits in the lungs, it can cause plugging of the airways (atelectasis). Mucus that stagnates can also become infected and that starts a vicious cycle. Because of the infection, one can't mobilize the secretions, and the infection itself produces more secretions, leading to pneumonia.

To cough well, one must have the ability for maximum inspiration, the ability to close the upper airway, and the ability for maximum expiration. Eighty to 100 percent of lung volume is necessary for the inspiratory component of coughing. The best tool for measuring lung volume and actual inspiratory capacity is pulmonary function testing (PFT).

There is also artificial inspiratory capacity. If one has weak inspiratory muscles and cannot take a deep breath, an individual may have the capacity for a deeper breath and not realize it. With PFT, the capacity to expand the lungs within the chest wall can be measured, as well as how much of the deep breath can be given by artificial means, such as a forced breath with pressure or IPPB. Although a person cannot take a deep breath on his or her own, it is possible to provide a deep breath and improve cough effectiveness. However, if the actual inspiratory and artificial inspiratory capacities are almost the same, there is no way we can improve the inspiratory component for coughing.

The expiratory component of coughing can also be measured by PFT, such as forced vital capacity, expiratory reserve volume, peak expiratory flow rate, and maximal expiratory pressure. If we can measure expiratory muscle strength, we have an indication of peak flow transients.

The inspiratory component of coughing can be improved by techniques such as IPPB, glossopharyngeal breathing, and breath stacking. Expiration can be improved by enhancing the existing expiratory muscles. Another way is to trigger spasms, especially in people with spinal cord injuries. I knew one person who was quadriplegic who could bring his arm forward, take a deep breath, and then hit his

stomach to trigger a spasm to produce a cough. A corset can help if there is abdominal muscle paralysis because it replaces some of the abdominal tone. Manual-assisted expiration is an abdominal thrust and a thoracic squeeze. Functional electrical stimulation (FES) is becoming more popular, using electrodes to stimulate muscles to make them contract at the time of expiration. The old Cof-Flator (OEM Co.) is now making a comeback as the In-Exsufflator (JH Emerson Co.).

❖ CHANGING EQUIPMENT AS DIAGNOSES CHANGE

CONGENITAL CENTRAL HYPOVENTILATION SYNDROME

(CCHS) — DEBORAH C. GIVAN, MD, RILEY CHILDREN'S HOSPITAL, INDIANAPOLIS, INDIANA

Riley Children's Hospital is the only children's hospital in Indiana, and its ventilator program is about 15 years old and currently includes 67 patients. Of those, 50 patients use tracheostomy positive pressure with an LP6 ventilator. Most of those children have a diagnosis of bronchopulmonary dysplasia. A few children use a Porta-Lung, and 15 children use nasal ventilation. Their diagnoses include spinal muscular atrophy, Duchenne muscular dystrophy, obstructive sleep apnea, meningomyelocele, myotonic dystrophy, and CCHS.

The family of the boy with CCHS approached us about the possibility of changing from tracheostomy to nasal ventilation about a year and a half ago, soon after we had switched a 7-year-old with spinal muscular atrophy to nasal ventilation. This was very successful, and we felt that we could probably switch the child with CCHS as well.

Our first attempt was unsuccessful, and further evaluation suggested that the child had been hypoventilating on his current ventilator settings. We made adjustments and sent the boy home to be reevaluated at a later date. He had been followed at home with an oximeter and tidal CO₂ machine in which intermittent gas levels were measured. In retrospect we do not think this system provided an adequate evaluation.

We performed another study, and this time we implemented nasal BiPAP®. We had difficulty adjusting the settings, but we achieved what we thought to be adequate settings at the time of discharge. We kept the child overnight in the hospital.

Subsequently he seemed to do well, but he developed an upper respiratory tract infection about two weeks later and had great difficulty. We felt again that we were unsuccessful. However, the cause for our failures turned out to be quite simple, and in a child without unusual disease, would have been dis-

covered right away. He needed a tonsillectomy and adenoidectomy. We tried nasal BiPAP® again, and this time it was successful.

We believe it is essential for the family to be fully informed of all the known risks and benefits of nasal ventilation, including the risk of disconnection and death, because it is easier for a child to play with a mask. The child must understand the use of the mask and why it cannot be removed. The family also has to be cooperative, committed, and compliant. One of the most difficult things for children is finding an appropriately fitting mask and headgear, and having a layered alarm system — more than one — to make sure that if there is an accidental disconnect, someone will respond.

put w/ his trach article

MUSCULAR DYSTROPHY — DANIEL M. GOODENBERGER, MD, WASHINGTON UNIVERSITY, ST. LOUIS, MISSOURI

The history of ventilatory support for neuromuscular disease was, until the mid-'80s, heavily influenced by external negative pressure ventilation, which is cumbersome and can lead to accentuation of obstructive sleep apnea. It is still obviously useful in some patients, but I have not used it in six years. I treat patients based on their symptom complexes and some screening. I question them about symptoms of night-time hypoventilation, including morning headaches, day-time sleepiness, swelling in the legs, etc. If the patient's vital capacity is less than 15% of predicted and they are asymptomatic, I have found it worthwhile to screen for evidence of nocturnal hypoventilation, usually with oximetry in the home.

One patient I had was a young man with Werdnig-Hoffmann's disease who had complaints of morning headaches, fatigue, malaise, and a vital capacity of about 200 ccs, with CO₂ elevation on room air at rest. An overnight sleep study showed severe repetitive desaturation associated with non-obstructive hypopneas. He was admitted to the respiratory ward (I do not use the ICU) to initiate nocturnal ventilation with nasal CPAP and an LP6 ventilator. He had difficulty with oral air leaks, nasal bridge irritation, and, because, he had supported his head lying down, he had an ear irritation that required some adjustments and foam rubber. However, after nearly four and a half years of successful nocturnal nasal ventilation, he developed a pneumothorax — a collapse of one of his lungs. He is one of two patients that I have seen with delayed onset barotrauma-related pneumothorax after years of ventilation, something which is not yet discussed in the literature.

My preference is to use a home ventilator as opposed to BiPAP® for several reasons, not the least of which is that it irritates me that the home care companies amortize the cost of BiPAP® in about six months, and I feel certain that is one of the reasons why they push it. In addition, there are no alarms on BiPAP®, and nasal resistance can vary dramati-

cally from day to day and hour to hour. I prefer to know that my patients are getting the tidal volume that I want them to have all the time.

Other complications in addition to pneumothorax and nasal irritation include dryness and congestion which usually respond to nasal irrigation with decongestants and application of humidification. Mask leak causing eye irritation in its most dramatic form can cause actual ulceration of the cornea. Gastric distention occurs in nearly everyone at the on-set, but in most people it goes away in about 10 days.

Noninvasive ventilation is important, but it is not the whole answer, and I think tracheostomy ventilation has an undeservedly bad rap. One of my patients, a young woman with muscular dystrophy, presented with symptoms suggesting nocturnal hypoventilation. She underwent initiation of nasal ventilation and had trouble with an oral air leak during deep sleep. She also had mild nares discomfort. For reasons that I am unable to explain she had substantial troubles with post-ventilation discharge from her nose.

Subsequently an episode of pneumonia resulted in emergency intubation and mechanical ventilation. Thereafter, despite repeated attempts, it was not possible to liberate her from the ventilator, and she underwent tracheostomy. This was complicated by difficulty in obtaining an adequately sized trach tube in her very narrow trachea that would allow speech. Today, she is very active, maintaining a telemarketing business and advising people with disabilities on a variety of subjects including air travel. She herself has flown successfully all over the U.S. and to Europe.

The Passy-Muir Tracheostomy Speaking Valve can improve the quality of speech for those who are able to be ventilated with either cuff down or cuffless tracheostomy ventilation. However, the same result can be achieved by putting a cork in the exhalation circuit of the ventilator; it is completely feasible, disposable, and costs about a nickel. In our experience with Passy-Muir valves, we found that multiple interventions were necessary by both physician and nursing staff, and included changing the tidal volume to adjust for leak, changing the respiratory rate, diminishing the ventilator sensitivity, and changing the trach size which was often the most time-consuming intervention. We concluded that Passy-Muir valves, though quite labor intensive, are safe and highly successful if the patient is intelligent and highly motivated, and patients with neuromuscular disease are much more likely to succeed than are people with obstructive lung disease.

SPINAL CORD INJURY — JOSEPH VIROSLAV, MD, ST. PAUL MEDICAL CENTER, DALLAS, TEXAS

The causes of spinal cord injury (SCI) are well known: motor vehicle accidents, falls, recreational activities such as swimming, and, increasingly,

violence in the form of gunshot wounds to the neck. The determinants of survival in SCI are basically the level of injury, the age of the patient, and the vital capacity.

The prevalence of SCI is up; about 240,000 patients, with the incidence per year 8,000-11,000 cases. The mean age at injury is 30 years of age. Fifty percent of the patients have cervical cord injury and that implies the majority of those patients have some respiratory difficulty.

We have had a concerted approach at Dallas Rehabilitation Institute for the last 16 years or so to transfer patients to noninvasive ventilation. However, there are patients who benefit significantly with a tracheostomy, particularly when they don't have adequate family support or attendant care. A high quad with impaired sensorium or upper airway dysfunction will require a tracheostomy. Of course, the disadvantages of tracheostomy are bleeding, infections, increased secretions, and difficulty in communication.

If the injury is at level C1-C3, the only muscles that function are the accessory muscles; those are the neck muscles at most. Injury at the C3/C5 level means there may be some diaphragmatic function. At level C5/C6, the upper intercostal muscles work, and from level C7/C12, the abdominal and lower intercostal muscles function.

Respiratory services with these patients is very important. We teach them how to do lung expansion and assisted coughing, we provide inspiratory muscle training so they can use the accessory muscles to maintain ventilation, and we teach glossopharyngeal or frogbreathing.

We looked at 10 years of experience with 700 SCI patients. We admitted 43 patients who were ventilator-dependent. The mean age was 33 -1/2 years; the mortality during the hospital stay was zero. Fifty percent (21) of the patients were level C3 or above and they were totally ventilator-dependent. Ten patients were level C4; eight patients were level C5; four patients were level C6 — all ventilator-dependent on admission. Of the total group, 32 had a tracheostomy and 11 used non-invasive ventilation.

Of the 32 with tracheostomies, nine patients were discharged with a tracheostomy; the tracheostomy was removed in the remaining patients. Of the 11 patients using noninvasive methods, five patients were completely weaned from ventilation. Usage varied from 24-hour use in 23 patients to 12-14 hours in 15 patients. During the night, a significant number of patients needed ventilation. We used a Lyon mask and PLV ventilator or a Lyon mask with BiPAP® or a strapless mask.

Followup after 40 months showed seven patients died (only one respiratory-related), nine remained with a tracheostomy, 16 patients had no tracheostomy. Hospital admissions decreased from 25% to 5%. Usage showed 24-hour ventilation in 17 patients,

nocturnal ventilation in nine patients, and 10 patients were weaned.

We have more than 200 patients (not all SCI) using home mechanical ventilation, and only 12-13 of those have tracheostomies.

DIAPHRAGM PACING — JOAN LAMB, RN,
THE DOBELLE INSTITUTE, GLEN COVE, NEW YORK

Traditionally, diaphragm pacing has been successful primarily in people with obstructive sleep apnea or with high spinal cord injuries, but there have been more inquiries about whether the newer types of diaphragm pacemakers would be of use in people with neuromuscular disease. The key is the amount of residual function left in the phrenic nerve and diaphragm. If the phrenic nerve is not working or the diaphragm cannot contract, then the point of pacing the nerve is useless. If, however, some residual fibers in the nerve have been saved, and the diaphragm does contract to some extent, there is a possibility with some of the newer equipment that diaphragm pacers can be more finely adjusted. Children with CCHS pace very well.

Our new diaphragm pacer is about the size and shape of a paperback book and weighs about a pound. The antennas and transmitter are the external components of the system. Surgery is required to implant a small electrode about the size of a fish hook onto the phrenic nerve and the receivers, about the size of three stacked quarters, into the adjacent tissues.

One of the things that has made possible the application of diaphragm pacing to new and different disease entities has been the ability to bring patients into our research labs at Glen Cove, New York, and to study and adjust the pacer, once the pacer has been implanted. We currently use a Macintosh computer that performs about 700-800 trials per day on one patient, usually in four to five hours. The computer can choose all of the different kinds of variations in the settings, for example the pulse switch of the pulse train, the pulse duration, the inspiratory time, etc., and can deliver breaths to the patient with all of these different variations.

Diaphragm pacing is also easier to manage from a distance, with the ability to send signals from the transmitter over the phone to our research labs to be analyzed. A report can be sent back to the doctor about whether the patient is pacing an optimal setting. We receive transtelephonic monitoring (TTM) signals from all over the world, and our engineers analyze them as quickly as they can.

The pacemaker costs in the vicinity of \$40,000, but the tradeoff is that one no longer needs ventilatory equipment and other disposables. The procedure is frequently done as an outpatient surgical procedure, and reimbursed by Medicare, and Blue Cross/Blue Shield and other private insurance plans. A five-year warranty is provided.

❖ LIVING AT HOME: OVERCOMING OBSTACLES

PEDIATRIC ISSUES — GEORGE B. MALLORY, MD,
CHILDREN'S HOSPITAL, ST. LOUIS, MISSOURI

A big issue with an infant or child with chronic respiratory failure is where should they be taken care of, where do they live? Most of these children start off in the hospital, usually in the intensive care unit, which is an awful place to live. It is noisy and it is bright for 24 hours. A number of institutions have hospital-based units for ventilator-dependent children. Longterm care facilities may be cheaper, but for children in particular, I think they are rarely a good option. Home is the obvious destination for children who are stable enough and whose families can handle it.

There may be a child who is medically stable, but who has a family that is not competent or uninterested. Do we expect every child, every adult with neuromuscular disease to live with a ventilator for months, years, decades before they die? I know a 39-year-old with Duchenne muscular dystrophy (DMD) who is obviously the product of incredibly competent, incredibly interested parents, and they have learned how to work the system. They all have a degree of motivation and self-esteem that most of us will never have. That does not hold true for everyone, and I am sure that his mother would not try to convince every family of a child with DMD that that has to be the outcome for them. Death is not always the enemy. Just because we can keep someone alive technologically does not mean that that will be a benefit for the patient and family. I agree that life with assisted ventilation can be good for many people, but not always.

Consider these different paradigms. An infant with central alveolar hypoventilation syndrome with a diaphragm pacer or noninvasive ventilation, reasonably bright parents and a reasonably informed physician, has a chance for an excellent quality of life. I would lobby hard for the system to provide for this child. A young child with severe neuromuscular disease and perhaps some moderate intellectual handicap also has a chance at a reasonably good quality of life, but it is going to cost his family (financially and emotionally) and society more. However, the child in a chronic coma or persistent vegetative state will never be able to appreciate the benefit of being alive, and society has had a tough time in deciding to provide for this child.

One key factor is of course payment sources. It requires vigorous lobbying on many different levels. There is the Katie Beckett case, in which Julie Beckett, her mother, went all the way to President Reagan to persuade him to intervene on the side of home care.

How do we define quality of life? Can we do it by IQ? I know some extremely bright people with very high IQs whose quality of life is not high, and I am proud to tell you that I have taken care of many

children and babies with very low IQs who, I think, have had a wonderful quality of life. It's the relationships that count.

Should physicians and nurses in 1994 be more concerned about saving money and reducing national health care costs or should doing good for their patients be their primary ethical imperative? I believe that beneficence — doing good — should continue to be the dominant ethic for physicians in the care of their patients, whether healthy or chronically ill, young or old.

FRANCE AND LONGTERM VENTILATION — PATRICK LEGER, MD, HOPITAL DE LA CROIX-ROUSSE, LYON, FRANCE

In France, many people who use ventilators live at home. There are several reasons for this. First, the existence of specialized units for home ventilation developed during the polio epidemics were maintained after the polio epidemics ended for other patients who needed respiratory assistance. Second, reimbursement by the health care system is 100 percent for individuals with a chronic disability. Third, there is a system of 32 regional not-for-profit home care organizations providing the equipment and maintenance and educating the individual, the family, and caregivers. At this time, there are approximately 8,000 ventilator users. With this kind of organization, there is not a problem living at home, as long as the disability is medically stable and mainly respiratory.

Thus, the nature of the disability of the individual using assisted ventilation is very important in regard to living at home. Kyphoscoliotic patients are very different from patients with an unstable disease like COPD. Individuals with ALS have a progressive disease, and it is necessary to adapt the quality of the care because they change very frequently in their level of dependency.

The mode of ventilation is another point. Non-invasive techniques are now more usable, and in our practice we always try to begin with noninvasive techniques before we propose a tracheostomy. It is more difficult for the person who needs a tracheostomy to return home because they are often medically unstable and the duration of ventilation is high.

Duration of ventilation is important also. It is different for the patient who needs ventilation only during the night and the patient who needs 24-hour ventilatory support. Motivation plays a key role, and I think points out a big difference between the French and the Americans. The French are really passive regarding their physicians. They do not have the reflex of the American consumer, and they usually accept easily what the physicians say. This is very important when it comes to evaluating who is a good candidate for ventilation. With this kind of passivity, everything seems possible. But finally, after days or months at home, the situation is uncomfortable and unmanageable.

Family support and family resources are easier in France because the family is relatively stable here, in terms of location. It is usual to have one's parents or relatives in the same area.

We have had much experience with ventilator users at home with good results. The number of hospitalizations after the return to home is low, as these individuals have very few medical needs. The quality of life is usually very good. There is a long survival rate, especially for polio survivors. It is possible to maintain them at home at a very low cost for the equipment and maintenance, about \$10 per day. But again, these people are at a very low level of disability with mainly respiratory problems or stable neuromuscular disease, and they are able to support themselves.

For others with more disability, the only support is the family, and there is a potential for negative consequences such as codependency. France does not have independent living centers like the U.S., and we don't provide support for attendant care. If we do find some caregivers, they are usually very close to the physician or the nurse and it is a very different situation.

Audio and video tapes of the conference are still available. For a complete order form, contact G.I.N.I., 5100 Oakland Ave., #206, St. Louis MO 63110-1406 USA, 514/534-0475 or FAX 314/534-5070.

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**Recent professional articles of interest to I.V.U.N. News readers, arranged in order of most current publication date.*

POLAND NEEDS VENTILATORS

Allen Goldberg, MD, Director of the Section of Home Health at Loyola University Medical Center, passed along this request he received from Dr. Miroslaw Tobiasz of the Department of Respiratory Medicine, Institute of Tuberculosis and Lung Diseases in Warsaw.

Dr. Tobiasz writes, "The major problem to enlarge the home care system in Poland is the shortage of ventilators for home use. They are not manufactured in Poland and there are no resources available in Poland to purchase them from abroad. The budget of the National Health Service is very limited ... I still think about development of home mechanical ventilation in Poland for patients that benefit from that mostly. As a Director of Long Term Oxygen Therapy [LTOT] Centre in Warsaw, I actually supervised 18 kyphoscoliotics with cor pulmonale who undergo LTOT as this is the only method of management of chronic respiratory failure available in my country. So I would like to ask if you, as the President of Association of Home Care Physicians, know about second-hand ventilators that might be offered to my country free of charge. If such a gift would be possible, we could probably arrange a transport to Poland through the Polish community in Chicago."

If you can help, please contact: Dr. Goldberg, Loyola University Medical Center, 2160 S. First Ave., Maywood IL 60153, 708/327-9114.

DR. SPENCER IS RETIRING

Geoffrey Spencer, OBE, MB, BS, FFARCS, is retiring as Clinical Director of Lane-Fox Respiratory Unit of St. Thomas' Hospital in London. Dr. Spencer has followed many British polio survivors, and encouraged and supported their efforts to live independently in their own homes, rather than in intensive care settings. In the late 1960s, Phipps Ward opened at St. Thomas' Hospital under Dr. Spencer's direction, with a home equipment maintenance program and attendant care. Dr. Spencer was also instrumental in the fundraising and building of the Lane-Fox unit in 1989.

Dr. Spencer will continue working until the end of this year with his successor, Dr. Adrian Williams, a Welshman who has been working in Los Angeles. *I.V.U.N. News* salutes Dr. Spencer and wishes him a long and happy retirement.



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Potpourri

❑ **Learning Objectives for Positive Pressure Ventilation in the Home.** The National Center for Home Mechanical Ventilation offers a 39-page listing of potential educational objectives to aid respiratory care professionals in customizing ventilator user and caregiver education. Available for \$5 postpaid from the National Center for Home Mechanical Ventilation, 1400 Jackson St., Room J105a, Denver CO 80206.

❑ **Domiciliary Ventilatory Support** is a policy statement of the British Thoracic Society regarding home ventilation, approved in 1993 by the Royal College of Physicians of London as their policy for the United Kingdom. John Shneerson, MA, DM, FRCP, Papworth Hospital was chair. For a copy, contact Dr. Shneerson, Papworth Hospital, Papworth Everard, Cambridge CB3 8RE England or the British Thoracic Society, 1 St. Andrew's Place, London NW1 4BL.

❑ **Electromagnetic Interference (EMI).** Is electronic medical equipment becoming increasingly vulnerable to electromagnetic interference — that is the waves given off by radios, televisions, computers, and the fast-growing use of cellular phones? A report in *The Wall Street Journal* this summer detailed some frightening malfunctions, from power wheelchairs moving erratically to faulty readings on apnea monitors to ventilator alarms going off inadvertently. The FDA screens some, but not all medical, equipment for EMI shields before reaching the marketplace, and several organizations are setting voluntary standards to address EMI. If any *I.V.U.N. News* readers have had problems with EMI and would like to share their stories in the next issue, please write to I.V.U.N., 5100 Oakland Ave., #206, St. Louis MO 63110-1406.

❑ **Tracheostomy Tube Adult Home Care Guide**, a 41-page booklet published by Shiley Tracheostomy Tubes to help home health care providers to teach home tracheostomy care is available free from Mallinckrodt Medical TPI, Inc., P.O.Box 19614, Irvine CA 92713-9614. 800/854-4071.

CALENDAR

COMMUNICATION APPROACHES FOR TRACHEOSTOMIZED & VENTILATOR-DEPENDENT PATIENTS, October 21-22, 1994, Goldwater Memorial Hospital, New York, NY. Contact Voicing!, 3857 Birch, Suite 194, Newport Beach CA 92660. 714/833-2710.



BREATHING PACEMAKERS, October 14, 1994, Harrison Conference Center, Glen Cove, NY. Contact The Dobelle Institute, 100 Lattingtown Rd., Glen Cove NY 11542-1243. 516/676-9292.



FIFTH INTERNATIONAL CONFERENCE ON PULMONARY REHABILITATION AND HOME VENTILATION, March 12-15, 1995, Hyatt Regency Hotel, Denver CO. Deadline for abstracts: November 30, 1994. Program Chairman: Barry Make, MD. Contact National Jewish Center for Immunology & Respiratory Medicine, Office of Professional Education, 1400 Jackson St., Room M/222, Denver CO 80206. 303/398-1359.



VENTILATOR ASSISTED CHILDREN'S CENTER (VACC) CAMP, Miami, April 1-7, 1995. Contact Cathy Klein, VACC Coordinator, Miami Children's Hospital, 3200 S.W. 60th Court, Suite 203, Miami FL 33155-4076. 305/662-VACC.