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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 mechanical ventilation.

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Underventilation

THE DIAGNOSIS OF UNDERVENTILATION FOLLOWING POLIO

G. T. Spencer, FFARCS, Consultant in Charge, Phipps Respiratory Unit, St. Thomas' Hospital, London

The diagnosis of underventilation after polio is not very different from the diagnosis of any other condition, but maybe it helps to go through it in order, because it can be confused easily with the underventilation and respiratory difficulties which occur in chronic obstructive airways disease. The distinction is important because the treatment is very different and the prognosis, given proper treatment, is very much better.

Firstly, you must be aware that the risk of underventilation after polio exists and that any other unrelated illness, operation or anaesthetic may cause trouble. Secondly, you must listen very carefully to the story. If I ever had to make do with only one diagnostic method, this is the one I would choose to keep. It usually gives more information than any other single indicator.

SYMPTOMS

I am going to list the various symptoms of underventilation which I have seen in 150 patients with polio over 20 years. Many of them were thought by the subjects who experienced them and even by their medical advisors to be caused by quite different things.

- There has to be some weakness of the trunk often including thoracic scoliosis.
- Loss of energy and a tendency to fall asleep easily during the day.
- General weakness and fatigue often affecting muscles which the

subject has not previously recognised to be polio weakened. This is a trap which can lead easily to the condition being missed if assessment is limited solely to muscle strength.

- A feeling that the air in the room is in some way bad.
- Claustrophobia - fear of confined spaces.
- Loss of mental concentration and reduced work capacity. This is often attributed by the sufferer to oxygen lack to the brain, but treatment by oxygen therapy alone is positively dangerous and in several patients led to an acute crisis and respiratory arrest.
- A sleep disturbance which can take various forms. These include difficulty in getting off to sleep with nightmares, waking during the night feeling desperately short of breath which often can be confused with heart disease, waking up feeling unrefreshed by sleep or with a headache not dissimilar to that associated with hangover due to alcohol.
- Frequent chest infections, often with difficulty in shaking off coughs or colds.
- Waking up with sticky saliva around the mouth.

Of course not everybody has all these symptoms and people can have some of them from other causes. Anyone who has more than two or three has grounds for suspicion and further investigation.

SIGNS

The signs of underventilation include quiet speech with fewer words per breath when speaking, or

difficulty in speaking for more than a short time. A reduction in breath holding time and the obvious use of unusual muscles when breathing, for example, the head, shoulders or arms. Difficulty in or a dislike of lying flat is particularly associated with paralysis of the diaphragm, that is the sheet of muscle between the chest and abdomen during breathing, and the special sign of scoliosis. Cyanosis (blueness of the lips and finger nails) is a very late sign of underventilation and its absence should not be regarded as sufficient reassurance that underventilation is not occurring.

MEASUREMENTS

Now at last and quite low down the diagnostic list we get to measurements.

- **Forced Vital Capacity**
Undoubtedly the most important is the forced vital capacity which has to be measured in several positions, for example, lying, sitting and standing where that is possible. Serious underventilation is unusual if the forced vital capacity is over three litres, though it can happen if other problems are present.

- **Pulmonary Function Tests**
Unfortunately, in people with weak muscles and low vital capacities following polio, formal lung function tests can be seriously misleading. Many of the measurements, for example FEV₁, are designed to measure the severity of chronic obstructive airways disease and not underventilation due to a restrictive defect such as muscle weakness.

- **Polycythaemia**
This term indicates an increase in the red cells of circulating blood and is commonly part of the body's adaptation to chronic underventilation particularly at night. It is not dissimilar to the polycythaemia seen in mountaineers who acclimatise to life at high

altitude and it is interesting that we have seen several patients with mild post-polio underventilation who got into very serious trouble after spending even a single night at high altitude while on holiday, or on a long overnight aircraft flight where cabin pressure can be reduced to the equivalent of around eight thousand feet.

- **Measurement of the Tension of Oxygen and Carbon Dioxide in the Arterial Blood**

While this is the most direct measurement of ventilation, the levels can often be normal during wakefulness by day, only becoming abnormal during sleep. Indeed, as is widely known, underventilation after polio occurs primarily during sleep and to prove that this is happening requires an overnight study of breathing during sleep. This must include a measurement of carbon dioxide tensions which is more difficult to measure reliably from the skin surface than is oxygen tension or saturation and many purported sleep studies can be misleading if both oxygen and carbon dioxide tensions are not measured repeatedly and regularly during the night.

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TREATMENT OF UNDERVENTILATION BY DAY AND BY NIGHT

G. T. Spencer, FFARCS, Consultant in Charge, Phipps Respiratory Unit, St. Thomas' Hospital, London

There are at least ten different methods of treatment for underventilation following poliomyelitis and the method selected must not only be fully effective medically, but also socially acceptable and practical in the home. In practice, all methods can be and are used in the home and I think the best thing I can do is to list each method

continued

with a brief summary of the advantages and disadvantages.

TRACHEOSTOMY AND INTERMITTENT POSITIVE PRESSURE RESPIRATION

This is normally used by people who need mechanical respiratory assistance both by day and by night and is probably the best method for patients with very severe muscular paralysis. Its advantages are that it is exceedingly effective, can be provided by relatively simple equipment which is small and convenient and can be attached to or incorporated in wheelchairs. Its disadvantages lie mainly in the tracheostomy which is always a route for the introduction of infection, can erode surrounding structures, and prevent glosso-pharyngeal breathing without an attendant being present to occlude the tracheostomy. Tracheostomy tubes can become blocked; speech is possible with a non-cuffed tube but it is intermittent during the inspiratory stroke of a respirator. Some patients who would undoubtedly benefit by it are reluctant to undergo tracheostomy because they feel that it increases their disability, makes them look even less like a normal person and prevents, for example, the wearing of a collar and tie which, even in these days, many believe to be part of being properly dressed.

IRON LUNG OR TANK VENTILATOR

This is also a reasonably efficient form of artificial ventilation. Its use is normally only justified for people who need artificial ventilation by night as well as for all or some of the day. Modern iron lungs such as the Cape Alligator or Rotator, are quick and easy to get into and out of, and we have recently designed and made one in which self insertion and release are possible for people with reasonable strength in their arms. The disadvantages of the iron lung are fairly obvious: it is very large in size and once inside a nonself-release tank, the user is effectively trapped and needs an

attendant to be released. Nor is it easily portable for overnight stays from home.

MOUTHPIECE INTERMITTENT POSITIVE PRESSURE BREATHING

This technique has become increasingly popular in recent years and a large variety of mouthpieces which stay in place during sleep have been developed. It is adequate for those with moderate respiratory weakness, but some of the more severely paralysed find that they can only use it for a limited number of nights in succession and need to resort to alternative devices from time to time. The equipment is small and easily portable, though the technique requires some practice and trial and error before it can be regularly used.

NOSEPIECE INTERMITTENT POSITIVE PRESSURE BREATHING

This is similar to the mouthpiece method and may have advantages in that it is less likely to produce obstruction of the upper airway. Development of adequate nasal masks is still continuing and many can easily produce soreness and discomfort over the bridge of the nose.

PNEUMOBELT

This is the only method which works by augmenting expiration. It is not particularly efficient and consists of a belt applied around the abdomen and lower chest which is intermittently inflated thus squeezing air out of the lungs. It is suitable only for people with paralysed abdominal muscles and diaphragm who need to use it during the daytime when sitting up. They usually need something more efficient at night. The equipment is small and the pump can be attached to a wheelchair. When used over long periods there is some evidence that it produces damage to the lower parts of the lung.

PROTRIPTYLINE

This is a relatively new drug which can be taken in pill form on going to bed. It acts by reducing the length and frequency of periods of Rapid Eye Movement sleep. This is a particular type of sleep which occurs in most people during which breathing is most disturbed. It is only effective for people with relatively mild underventilation and is particularly suitable for people with congenital or non-paralytic scoliosis. It has the great advantage that no equipment is required, but, unfortunately, the drug has quite serious side effects producing constipation and dryness of the mouth. It can also cause temporary impotence in sexually active men. In general, it is rarely suitable for people with poliomyelitis, many of whom have a distressing tendency to constipation anyway.

There is no doubt that all these different methods have a place and an adequate medical centre should have them all available and be able to select whichever one, or combination of several, is most suitable and effective for each individual. Unfortunately, equipment manufacturers prefer making large numbers of one or two types of machines rather than small numbers of a variety and, at present, adequate designs of all these devices are only available in a few countries.

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ED: These two papers were presented by Dr. Spencer at the International Symposium on Poliomyelitis in Munich on April 7-9, 1988.

STAGES OF PSYCHOLOGICAL ACCEPTANCE OF NOCTURNAL VENTILATION

Lilly Henderson

I. DENIAL. Personal experience with this stage began several years ago when new weakness, fatigue, and lowered immunity to respiratory infections began to be a pattern of life. At first, I tried to ignore these changes, thinking it was only my imagination or that I needed vitamins. When I was told that I would inevitably need nocturnal ventilation, "fear of the unknown" became a strong force that filled my waking and sleeping hours. It is difficult to indicate clearly the beginning and ending of each stage as sometimes they overlap with a period of "slipping" back to a former phase.

II. MOURNING. People have to adjust to loss whether it is death of loved ones, divorce, broken trust, "security blankets," or, in my case, loss of fiercely fought for and cherished independence. The old cliché, "time heals," is applicable at this stage. You must allow physical and mental adjustment processes to occur and coping mechanisms to develop without reference to a time frame. Each individual must be allowed this "healing" before a higher plane can be achieved.

III. SELF-IMAGE CRISIS. What happens to mind and soul when life, as you know it, changes? Daily routines ingrained to automated functions halt abruptly, playing cruel jokes with the mind as it slowly accepts and adjusts to new reality. I became a mother who could no longer shop for groceries, birthdays, or Christmas, hide Easter eggs, drive to McDonald's, or make a surprise visit to grandma's. I began to wonder how my changing life appeared to others. I no longer felt people saw me as an independent, enjoyable friend to be around. Former dislike for doing laundry or dishes became desire for accomplishment. Sexuality once

continued

remolded from a battered image had again been thrown askew. What is left? During this phase, you struggle to answer that question.

IV. SELF-WORTH ASSESSMENT. While reaching for independence during the past 20 years, a foundation of inner will power evolved that has remained the core of surviving all the changes that have occurred in my life the past year. You reach back to the basic, "true" meaning of life, which helps you reestablish feelings of self-worth. Physical accomplishment must be measured with a different yardstick. It no longer equates to success. The essentials change and you focus on your contributions to your work, family, peers. The unknown and fear of unanswered questions are still present, but can be dealt with slowly and with determination. For me, the touch of my child's hand and his trust that I will always love him are vital driving forces to look forward to each new sunrise.

V. COPING SKILLS DEVELOPMENT. You regain bits and pieces of self-confidence through a work task successfully accomplished, a sandwich made, a flirtatious encounter, a friendship shared. Fear expands beyond Maslow's survival instinct to include a broader picture window on the passing world. The foundation becomes firm once more and you venture forth with walls reinforced with hope, support, optimism, trust, self-confidence, and love of family and friends. A special friend visited me recently who had not seen me since prior to my changed world. She told me she had been anxious about seeing the effect of all the changes on the person she had always known and had prepared herself to understand. I'll never forget her next words, "But, you are still Lilly." Her words showed me that coping skills were present, both internal and external.

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PERSONAL PROCESS OF COPING WITH UNDERVENTILATION

Lilly Henderson

I contracted polio at the age of ten in 1959. Initially, I required the use of an iron lung for five months. Subsequently, I used a rocking bed for six months at which time it was decided that I no longer needed respiratory assistance. My adolescence was a time of intensive physical therapy, functional training, strong family support, and development of self-determination in striving for independence.

In 1981, while four months pregnant, I began experiencing increasing levels of carbon dioxide and oxygen desaturation. This crisis required the intervention of 24-hour ventilator support throughout the duration of my pregnancy and was accomplished by a tracheostomy. I became the mother of a beautiful little boy and discovered the perils and pleasure of parenting from a wheelchair.

By that time, I was working as the assistant director of the Independent Living Center in Birmingham, Alabama. In 1984, I developed pneumonia requiring intensive care and ventilator support for a period of three months at University of Alabama Hospital in Birmingham. I relocated in Montgomery, Alabama, to accept a position as program specialist with the State of Alabama Client Assistance Program in May, 1985.

I have always lived a very independent life. I have been active in work, volunteerism, socialization, disability advocacy, and parenting. But, beginning several years ago, a series of new physical problems began to affect my life. These new problems, called the late effects of polio, require new coping skills which involve learning to adjust to progressive disability of unknown limits and to dramatic lifestyle changes. Coping

has challenged me as a person and as a professional to accept and continue life in a positive direction.

This feat would be impossible without a support system. My support system includes a special extended family, personal and professional friends, the State of Alabama Homebound Program, Montgomery Home Health Services, and knowledgeable physicians who are willing to work toward "quality" existence.

The physical symptoms I began experiencing included a lowered fatigue threshold, loss of muscle strength and range of motion in the left arm and shoulder, gradually increasing levels of carbon dioxide, and nocturnal hypoventilation with oxygen desaturation.

In 1986, my pulmonary physician predicted it would be inevitable that I would need a portable ventilator for nocturnal ventilation in the near future. The inevitable became reality on June 26, 1987 and now, through home care services, I sleep with the aid of a LP6 ventilator. Currently, I do not require any type of respiratory assistance during my waking hours.

I have experienced many problems associated with using the tracheostomy approach to ventilatory support. Initially, these problems included regrowth of granulation tissue, poor humidification, constant need of suctioning, and a great deal of pain and trauma when changing the tube.

This procedure involved mental stress because numerous times I saw the face of my frightened child huddled in the corner of the room crying because he did not want or understand what was happening to his mother.

Initially, I used an adult Shiley 4, cuffed, fenestrated trach and during the day I would develop mucus plugs and/or tissue regrowth through the fenestration. These plugs would dry and cause bleeding upon removal. Suctioning alone would not clear the passage, requiring insertion of the inner canula which pulled or broke loose the obstruction.

In August, 1987, I had surgery for removal of granulation tissue which proved unsuccessful; within two weeks the growth process began to repeat itself. A week before Thanksgiving 1987, I was hospitalized for an upper GI problem. During a routine change of the tube they realized it was impossible to reinsert the same size trach. So, I changed to a Pediatric 3, non-fenestrated, non-cuffed tube. I also changed to a Passy Muir Valve, which improves my ability to speak, reduces infection, allows air flow through the nasal passages, and recreates a sense of normalcy in conversation.

This system is working very well for me at this time and I am physically tolerating the abrupt daily change from breathing on my own to total assistance while on the LP6 with minimal stress. I am investigating face masks and CPAP. Some day, I may decide to eliminate the trach and try one of these methods instead.

Psychologically, I have come a long way since June of 1987, but remain aware that periods of depression still exist and coping mechanisms still need to be used.

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PROBLEM: PHYSICIAN EDUCATION

David Sherman

I had polio at age five in 1954. I couldn't move or talk one day but it went away and I was never on a respirator. I recovered and was very active physically for many years despite recurring problems, including severe sleep disturbance, respiratory trouble, and numerous musculoskeletal problems.

I also developed extreme cold sensitivity, very high blood pressure, congestive heart failure, voice/swallowing problems, twitching muscles, and other strange problems which were never diagnosed properly until this last year.

My long-time general practitioner and I finally figured it all out by getting the International Polio Network (IPN) literature on the late effects of polio. He and I have had a terrible fight to get any help for me because I've been unable to work for a long time, had no money, and the state and federal agencies did not, at first, believe in the existence of the late effects and then did not think I had them.

We are still having lots of problems with SSI/AFS/Medicaid programs and the health care profession. One doctor prescribed a sedative, then a tranquilizer for my apnea sleep disturbance (blamed my rapid breathing and poor sleep on "anxiety."). He recommended aerobic exercise (walking one-half to one mile a day), but never questioned why I was "winded" just sitting in his office! He just assumed my symptoms to be "anxiety."

Because the other doctors I saw totally overlooked my respiratory problems and severe apnea my SSI claim was rejected over and over. Finally, I did win my case,

after having to fight their reports to SSI.

Again, it was IPN's and IVUN's literature (the polio handbook and the proceedings of their polio conferences, etc.) that turned the tide and convinced the judge and the SSI doctors that my own general practitioner's diagnosis of the late effects was probably accurate.

Now, at long last I have a respirator (PLV-100). Medicaid is renting it from Lifecare. I use it as much as I can - mostly at night, but intermittently throughout the day too. I am having pressure sores on my face (with C-PAP mask) and dental and jaw pain from a Bennett mouthseal. Reading about others' mask problems in IVUN has really helped me to keep up with new breathing equipment and to feel better about my own difficulties "adjusting."

The IPN/IVUN literature literally saved my life. The handbook first alerted my doctor and me to the seriousness of my rapid breathing and easy windedness and severely disturbed sleep.

So, very largely due to this polio information, I am no longer being denied food stamps, financial (disability) help, Medicaid, a ventilator, a heart machine, a wheelchair, braces, a hospital bed, home nurse care, and nursing home care. I am no longer being treated like a neurotic or fraud, trying to get attention or to get out of working. 福

ED: The Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors includes useful sections on respiratory insufficiency, respiratory therapy, ventilators, and home mechanical ventilation. \$6.75, postpaid, from IVUN.

UNDERVENTILATION; A WARNING
Richard L. Weiler

Central Alveolar Hypoventilation Syndrome - my doctor's description of a condition which was slowly destroying me and of which I was alarmingly ignorant.

I am a polio survivor (1955) who relied on mechanical ventilation for approximately a year after the disease struck, six weeks in an iron lung and the remainder of the time on a chest shell or cuirass and a rocking bed. After this, it was decided that I could breathe adequately without mechanical ventilation and, at the age of 16, I began to cope with the severe paralysis which remained, a process which has taken a lifetime.

After six months at the Georgia Warm Springs Foundation, I returned home to Nebraska to complete high school. After that, college and law school at the University of Missouri, Columbia. Since 1968, I have been employed by the State of Missouri, currently with the Attorney General's office.

It is hard to remember when the first symptoms of breathing difficulties began to appear, but it was well before any public discussion of the "late effects of polio." I began to experience difficulty in sleeping at night, I started having vivid dreams and sometimes nightmares, and I seemed to wake up often. This, of course, led to fatigue during the day.

Six years ago, my local doctor became concerned about continued high blood pressure readings and I started taking blood pressure medicine. Approximately four years ago, I woke up in the middle of the night with a tremendous ache in my chest and stabbing pains down the left arm. Fearing a heart attack, I was rushed into the emergency room of the local hospital. Tests

disclosed no damage to the heart but my breathing difficulties at night were noticed. Upon my physicians's advice, I started using the chest cuirass for breathing assistance at night.

Although the cuirass provided some relief for the next several years, the problem started accumulating again. My sleep patterns became very erratic. I would sleep heavily for an hour or two and then spend the rest of the night awake or in a shallow dream stage. I had morning headaches, tiredness during the day (at times I could not keep my eyes open), and at times I was not mentally alert. Sinus conditions from allergies aggravated the condition and made life miserable. At times I would be so tired at the end of the day that I could barely speak audibly.

Finally in the fall of 1987, a doctor suggested a sleep test. Results indicated that the symptoms were caused by a carbon dioxide buildup because of inadequate ventilation at night. The doctor recommended a return to the iron lung at night. He suggested that daytime use might be necessary also in the future.

This was a real shock for me. My health had reached a point where continued employment seemed in jeopardy. Now the doctor was telling me that the cure might also make it impossible to continue employment. I decided to seek a second opinion from someone more knowledgeable on post-polio problems. After soliciting information from various sources, I decided to contact Dr. Oscar Schwartz in St. Louis. Dr. Schwartz called me to discuss my condition and followed up with a letter. As a result, I checked into a hospital in St. Louis in early December 1987.

I have heard weight lifters say, "no pain, no gain." That describes my five-day stay in the hospital.

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They took so many blood samples that I think I am qualified for a Red Cross pin. I was introduced to positive pressure ventilation using a nasal mask which promptly blistered my nose. However, the gain was tremendous. The first night I used the nasal mask and positive pressure I slept better than I had in years. By the end of five days the nasal mask no longer felt alien and I was sleeping soundly through the entire night.

I now wake up in the morning refreshed with plenty of stamina for the entire day. The morning headaches have receded and the periods of mental fatigue have disappeared.

The change has been obvious to all those around me. For the first time in a long time, I am enjoying myself both at home and at work. Even the blood pressure problems have disappeared. After evaluating the situation, Dr. Schwartz discontinued all of the blood pressure medicine.

Any polio survivor who required ventilatory support in the past, or whose current ventilation system is not allowing sound sleep, should seek the advice of a knowledgeable medical specialist. If you are not sure who that might be, contact the Gazette International Networking Institute, 4502 Maryland Avenue, St. Louis, MO 63108. I will bet my last dollar that Gini Laurie can provide you with the necessary information.

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Reprinted from the REHABILITATION GAZETTE (Vol. 28. No. 2. 1987) and POLIO NETWORK NEWS (Vol. 4. No. 2. 1988)

GET HELP AND GET HAPPY
Barb Van Davis

The headline, "Underventilation: A Warning," in the Spring 1988 POLIO NETWORK NEWS, grabbed my attention the minute it cropped up in my morning mail. In it, a Missouri lawyer wrote about immobilizing symptoms he experienced which threatened his job security, not to mention his quality of life.

I had the same symptoms he did. There were my innermost sensations, neatly clustered and peering back at me from the printed page. Mind you, I hadn't realized they were all part of the same picture. I was exhausted all the time. I felt light-headed, and woke up more and more at night feeling as if I hadn't been breathing. I went to a sleep lab two years ago, I was getting more tired, and began waking up gasping for air, my throat muscles aching, my head throbbing. My feet were swollen, I felt mentally dull, I forgot things.

He and I both had tried to solve this problem before. He'd tried a chest cuirass at night to help him breathe, but after a brief respite his symptoms persisted. After a sleep test a year ago, he was told to return to the iron lung due to the high levels of carbon dioxide in his body from inadequate nighttime ventilation. I was told that if my problem worsened, I could find relief by having a tracheostomy and hooking myself up at night. I'm sure you understand how thrilled we both were with this iron lung-tracheostomy stuff.

OK, so here's the picture. I'm an MA level psychologist getting my doctorate in clinical psychology; I'm the mom of two active teenage boys; I'm a newlywed, and my husband and I are rehabbing a 150-year old home. I needed these symptoms like I need another hole in the roof. So, I showed my

husband the article, and this is just what happened.

Jeff called Dr. Oscar Schwartz, the pulmonologist in St. Louis who'd come right by my Missouri friend; the doctor was paged, a conversation ensued, and five days later I checked into St. Mary's Hospital in St. Louis.

The first night, I slept with a finger oximeter on. This is a little plastic thingamabob that fits over your finger like a glove, and gives a digital readout of your pulse rate and oxygen level from moment to moment. It also graphs a printout of the results. Mine showed that, though my oxygen saturation levels average in the 90% range during the day, in sleep they drop below 60%, in a cyclical fashion. (The sleep lab had misunderstood the results of my test because this condition is rare in the general population, but it may occur in polio people.) The next night I slept fitted with the oximeter again, but a positive pressure ventilator was added. This compact box (about 12 inches on a side) pumps regular room air and helps you breathe; to use it, I just slip a tiny soft plastic mask over my nose (not my mouth), and flip a switch.

Here's the exciting part: after just a few hours sleep, I felt my energy level soar! Now I'm productive in the daytime and deeply, gloriously asleep at night. Wearing the mask at night does take some getting used to, but I feel so great that a few weeks of adjusting seems a ridiculously small price to pay. I brought the ventilator home with me, and I can't tell you how happy we are with it.

The ventilator is small, noiseless. All you do is put the mask on whenever you decide to go to sleep. When it's unplugged, it automatically runs on a battery. We've gone camping with it, and it was a real pleasure - you can carry

it in one hand. Insurance will usually cover the cost. The only cost insurance doesn't cover comes from all the things I've been buying because now I feel like shopping again.

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(ED: If you are employed and want to continue working, apply to your state vocational rehabilitation agency for coverage of a medical examination, equipment, workplace adaptations, etc.)

Reprinted from POLIO CONNECTIONS (Vol 3. No. 10. 1988)

THE HAZARDS OF OXYGEN FOR POLIO SURVIVORS

Mary Ann Hamilton

A little over three years ago, I discovered that the problem was not going to go away - no matter how hard I tried to ignore it. The nights were long. Night after night I watched the red numbers on our digital clock click off the hours as I tried to shut my eyes and get some sleep. When I finally fell asleep just before dawn, it was into a deep oblivion that caused my husband, Ed, concern when he had to shake me awake before he left for work. Awakening was not all that pleasant as my head usually ached and I felt exhausted.

What could be wrong? My chest shell fit as well as ever even though through the years we've had to boost the negative pressure up to twice the amount I'd started using 33 years ago. But a respirator is a respirator, right? Wrong!

My flight to the hospital in '54, gasping for breath, was rewarded by a tracheostomy, and an Emerson iron lung for the next eight months.

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When I returned home to my husband and four children I was a walking, "upside-down" polio mother and wife. I used the chest shell 14 hours a day. I had a trach tube that required suctioning several times a day so the family also acquired an attendant. The trach tube was another crutch I couldn't do without - until 10 years later when a newly hired attendant, whose desire for alcohol exceeded her desire for steady employment, couldn't aim the catheter to connect with the trach opening. "I don't need this," I realized at last, and the silver tube disappeared into a drawer where it remains, corroded by time.

When the Bantam Positive Pressure respirator was made available to me, I used it for brief respites in the afternoon and for traveling in the car. My chest shell powered by the 170-C Monaghan still maintained me sufficiently during the night.

About 10 years ago, my pulmonologist warned, "Sometime in the future, your respirator is not going to give you enough ventilation." But I felt fine, then. His warning was not followed by any advice as to how to help ward off this shadow he hung over my life.

During the ensuing years my daughters and I started our own business. I worked four or five days a week for eight years, using the Bantam during the day to keep up with the pace. During our eighth and last year, I was using daytime respirator assistance more and more hours. After the store closed my days at home began to deteriorate. I couldn't seem to stay awake during the day and I couldn't close my eyes at night.

One morning my attendant, who has been with me for over 20 years, lifted one of my flail arms to shove it into a blouse sleeve - an old blouse I've had for many years. The sleeve stuck half way up to my

swollen arm. I stepped onto the scale and saw the arrow point 15 pounds beyond my normal 110. Good grief! What's happening? Even my lips were blue.

The day my doctor had warned me about had arrived. My chest shell was no longer giving me adequate ventilation. My pulmonologist took an oximeter reading and discovered my oxygen saturation was down in the 80's. I was retaining carbon dioxide so my body was not getting the oxygen it needed. My swollen arms and feet were retaining fluid (edema). My doctor, who is not knowledgeable about post-polio (or even polio for that matter,) prescribed two liters of oxygen 24 hours a day....From the moment that oxygen tube started forcing oxygen into my nostrils I knew I hated the feeling it gave me. (I couldn't explain it but it seemed to debilitate my strength.)

However, I began to sleep better and with the oxygen tube trailing behind me all over the house, I could stay alert during the day. About this time I wrote to Gini Laurie and mentioned that I was using oxygen. The minute my letter reached 4502 Maryland Avenue my phone rang. It was Gini advising me....warning me, that oxygen was hazardous to respiratory polio people. She reminded me about an article that was in the REHABILITATION GAZETTE explaining why.

With Gini's warning pushing me into action, I went through Mercy Hospital Post-Polio Clinic and was advised to get a sleep study. The sleep study revealed that 2 liters was too much oxygen but I still needed 1 liter 24 hours a day. For the next three years - although Gini's warning worried me - I seemed to get along adequately. Then the sleepless nights and drowsy days began again.

I wasn't getting enough ventilation. Was it time to go back to using my trach again? During those

three years I tried a nasal mask and a lipseal but my open trach, even securely taped, leaked like a steam whistle.

Luckily, about this time, June of 1988, we drove to St Louis to attend the International Polio Network's Support Group Leaders' Workshop. We met Dr. Oscar Schwartz, a pulmonologist. He spoke about the hazards of using oxygen for some of us with respiratory problems because of polio. Those who have 50% or less breathing capacity have a 50% chance of having Central Alveolar Hypoventilation Syndrome.

With a bit of friendly persuasion, I checked into St. Mary's Hospital in St. Louis under Dr. Schwartz's care. During the next three days, (with Ed sleeping in a lounge chair beside my bed), Dr. Schwartz tackled my breathing problems one by one. He redesigned an Olympic trach plug to fit my trach opening and neatly closed off the leak. He fitted me with a C-PAP nasal mask. That first night, he patiently coaxed me into believing that I just might survive.

The night progressed with the oximeter pinched to one ear while the beeping monitor assaulted the other. The nurses and respiratory therapists tiptoed in hourly, swishing flashlights and climbing over my sleeping spouse.

I have been home in mile-high Colorado for months. I sleep soundly all night and wake up feeling rested and refreshed.

Perhaps the hardest part of making a change is thinking about it, realizing that time is slipping by and you must make a decision. I hated the thought of changing from my familiar, hugging security of a chest shell. But I discovered that a few ounces of plastic strapped to my nose is just a new device....I can live with.

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PORTA-LUNG FOR TRAVEL

Marsha Ballard

About five years ago, my father wanted my husband and me to be able to travel again. When I heard about someone in Colorado making portable lungs, Pop flew to Denver and talked to Sunny Weingarten. Sunny had designed and built fiberglass and aluminum lungs for himself and had recently decided to make them for others. Pop was his first customer. Now, several dozen home care medical companies handle his marketing and sales, but I would recommend calling him directly (303-288-7575). The current list price is \$5,395 to \$5,995, depending on the size. The Thompson pressure unit to pump it is purchased separately.

I highly recommend the Porta-Lung. With a tightly sealed collar, the pressure will go to 40 cm. of water or higher, and the rate is easy to adjust. Mine fits in our RV in place of the long couch. The head end is designed to have the regular spiral collar assembly fastened on the outside or the inside, so I can adjust my own collar. It weighs only about 100 lbs.

Sometimes I get that helpless feeling because the medical 'experts' seem totally ignorant of my problems. One of our local hospitals has an iron lung, but my husband had to show the respiratory therapist how to run it.

It helps when I can talk to someone else with the same problems. Linda Pickle, who works at TIRR, has been sleeping in the lung and C-PAP combination for several years. When I started to use the combination too, she tipped me off about fixing the head straps and, of course, Sunny shared his experience in designing portable lungs. There's a lot of us out here, if we'll just make ourselves heard.

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BLITZER REPORT 3
NOSE-POSITIVE VENTILATION MASKS
Bud and Dalia Blitzer

Our last report was in November 1987, so long ago that by now you figured either there was no progress to report, or you've forgotten what it is we're reporting about. To refresh, we're the ones who are trying to encourage manufacturers to speed the development of more workable, affordable, and comfortable nose masks for us ventilator people.

Unhappily, we still don't know of a place where you can get the nose mask of your dreams off the shelf, but there is reason to be encouraged. The German inventor of the mask Adolf Ratzka has been using so successfully in Sweden has now been connected with a leading manufacturer in the USA. The novelty of this mask design is that it has a gasket between the mask and the skin that fills with air on the inhale cycle and releases air on the exhale cycle. This tends to reduce air leakage greatly when positive pressure is building in the mask, without tightening the headstraps to the point of discomfort.

When I tried the first prototype it seemed to confirm the merit of this approach. There are still some problems to work out (such as how to sterilize the mask, as the gasket traps water during the soaking process, skin moisture accumulation under the mask, etc.), but now we have a leading manufacturer interested enough to commit product development resources to a mask that has the potential to work well, be economically produced, and feel comfortable without custom fitting.

Other groups in France, Australia, and the U.S. are working on designs of their own. We will all meet to share our ideas at G.I.N.I.'s Fifth International Polio and Independent Living Conference. (May 31-June 4,

1989. Sheraton St. Louis Hotel.) A special mask session is scheduled during the afternoon workshop of June 3 on Home Mechanical Ventilation.

Meanwhile, if you can help speed up the progress, please write to us, The Blitzers, 400 South Saltair Avenue, Los Angeles, CA 90049. (213) 476-9343.

POTPOURRI

FROGBREATHING TAPE. Order from: Mrs. Kelsey, Respiratory Therapy Supervisor, Aberhart Center, University of Alberta Hospitals, 8440-112 Street, Edmonton, Alberta T66 2B7, Canada. \$50 Canadian.

LIFE-SUSTAINING TECHNOLOGIES AND THE ELDERLY. GPO Stock 052-003-0107407. \$19. SUMMARY. \$2. Order from: Superintendent of Documents, Government Printing Office, Washington, D.C. 20402.

LIFECARE, 655 Aspen Ridge Drive, Lafayette CO 80026, has two new publications that should be in your files: Respiratory & Accessory Power Usage Chart for LIFECARE equipment and the list of its international representatives. The latter is invaluable for travel to almost any place in the world.

HIGH FREQUENCY VENTILATOR is being tested for the Food and Drug Administration by Dr. Jim Hurst of the University of Cincinnati Medical Center.

THE MEDICARE CATASTROPHIC COVERAGE ACT OF 1988. "Sec. 429. Demonstration Projects....The Secretary of Health and Human Services shall provide for up to 5 demonstration projects, for up to 3 years each, to review the appropriateness of classifying chronic ventilator-dependent units in hospitals as rehabilitation units."

1989 CONFERENCE CALENDAR

January 26-27. INTERNATIONAL CONFERENCE ON HOME MECHANICAL VENTILATION. J.I.V.D Service de Reanimationon - Assistance Respiratoire Hopital de la Croix-Rousse, 93, Grande-Rue de la Croix-Rousse, 69317 LYON Cedex 04 - France.

March 30-April 1. SYMPOSIUM ON LIFE THREATENING CONDITIONS; SELF-HELP GROUPS AND HEALTH CARE PROVIDERS IN PARTNERSHIP. McCormick Center Hotel, Chicago, IL. Write: Hannah L. Hedrick, PhD, American Medical Association, 535 N. Dearborn, Chicago, IL 60610.

April 5-8. WEBB-WARING INSTITUTE ANNUAL SPRING PULMONARY COURSE. "Respiratory Care from Prevention to Disease Care." Write: Louise Nett, RN, Box C-321, 4200 East 9th Avenue, Denver, CO 80262.

May 31-June 4. FIFTH INTERNATIONAL POLIO AND INDEPENDENT LIVING CONFERENCE. Sheraton St. Louis Hotel, St. Louis, MO. Write: Gini Laurie or Joan Headley, International Polio Network, 4502 Maryland Ave., St. Louis MO 63108.

Wed. May 31: Independent Living Worldwide - Diverse Effects of National Social Policies. Raising Expectations.

Thurs. June 1: International Progress - Medical and Social. Research. Late Effects of Polio - Symptoms and Management: Fatigue. Underventilation. Weakness.

Fri. June 2; Late Effects of Polio - Symptoms and Management: Pain. Exercise. Orthotics and Seating. Psychological Adjustment.

Sat. June 3. Ethical Challenges and Social Policies of Disability and Aging.

HOME MECHANICAL VENTILATION WORKSHOP

- Anesthesia in Severe Disability
- Tracheostomy Alternatives
- The Changing Ventilation Needs of Polio Survivors
- Swallowing Management
- Muscular Dystrophy - Informed Choices
- Home Ventilator Maintenance
- Creative Funding for Home Ventilatory Support
- Travel with Ventilators
- Living With a Ventilator for 30+ Years
- GPB and New Face and Nose Masks

Sun. June 4. Special Interest Workshops

June 2-4. ABILITIES EXPO-MIDWEST. Concurrently with FIFTH INTERNATIONAL POLIO AND INDEPENDENT LIVING CONFERENCE. At adjacent Convention Center.

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福 REHABILITATION GAZETTE

International Journal of Independent Living by Individuals with Disabilities

If your professional interest is in home mechanical ventilation or if you are a ventilator user, you should be a reader of the REHABILITATION GAZETTE. Every issue is a rare collection of subjective accounts by ventilator users of all ages - many of whom have lived, worked, and travelled for more than 30 years while using a ventilator.

Ever since this unique international journal was founded at a respiratory polio rehabilitation center in 1958, it has been publishing articles by health professionals and ventilator users with all types of disabilities living at home.

These life experiences of ventilator users are an invaluable source of ideas, inventions, and motivation for other ventilator users, their families, and health professionals.

The REHABILITATION GAZETTE covers every phase of living productively and independently in the community, as well as specialized information such as camping, foot-controlled steering, education by telephone, homebased businesses, mouthsticks, and ventilator-related information that includes underventilation, glossopharyngeal breathing, positive pressure by face and nose masks, tracheostomy speaking valve, portable iron lungs and rocking beds, and adapting to ventilators.

Extra Special Bargain! Send a stamped, self-addressed No.10 envelope for the inventory clearance sale: Single back issue \$4 plus \$1 postage. Complete set of 23 back issues: \$60 plus \$8 postage.

Extra Special Issue! To celebrate its 30th anniversary in 1988, the GAZETTE is publishing a double issue at the close of the year. The special issue features the life experiences of long-time ventilator users with their reflections and analyses of the motivation, support systems, and training that enable them to live fully in their communities. Subscription: \$15 individuals. \$20 institutions. \$3 extra for outside USA and Canada.