VENTILATOR USERS CAN SURVIVE THE SYSTEM WITH YOUR HELP

Margaret Pfrommer Memorial Lecture in Long-term Mechanical Ventilation

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Special thanks to...

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Front row (l-r)

Sheryl Rudy, SherylzArt, newsletter and web designer
Joan L. Headley, Executive Director
Gayla Hoffman, Gayla Hoffman Associates, newsletter editor
“Networking links people who share common needs or common goals. Networking is a support system. It is a method of self-organizing. It is the structure of a social movement. Most of all it is a method by which people get things done.”
“I am just a normal person who happens to be lying down. That is how I feel. Even though my physical form is a little different, my life doesn't have to be.”
IVUN’s mission is to enhance the lives and independence of users of home mechanical ventilation through education, advocacy, research and networking.
“The [phone] calls usually start by asking for the name of a nursing home that will take people on ventilators. I react violently to the suggestion and remind them that they do not need nursing. They need a pair of hands that they can direct. They do not need to be buried alive in a nursing home. They need to continue to live their lives as they choose.”
How many ventilator users? In 1990, it was estimated that there were 11,419 in the US [most in acute care hospitals (62%), chronic care hospitals (22%), at home (20%)].


Eurovent survey, 2005. The surveys provided data on 21,526 HMV users in the 16 European countries surveyed (estimated prevalence was 6.6 per 100,000). HMV centres were defined as any hospital or outpatient unit that initiated or prescribed HMV and/or co-ordinated HMV services. A total of 329 centres completed the full survey, giving a response rate of 79% by user numbers. Some of these users may be described twice by, for example, French Associations and Hospital units.
Who is a ventilator user?
What is ventilation or respiration?
Ventilation or respiration is the process responsible for moving air in and out of the lungs. Inhalation is the process during which the exchange of oxygen (O₂) and carbon dioxide (CO₂) occurs in the alveoli of the lungs. The diaphragm is a sheet of muscle at the base of the ribcage and the lungs are inflated by the contraction of the diaphragm and the intercostal muscles between the ribcage. When these breathing muscles relax to a venteminal position, the lungs are deflated by gravity and pressure within the body. Full inspiration involves the diaphragm and ribcage muscles working together to expand the lungs.

What is a ventilator?
A ventilator, also known as a respirator, is the equipment used to mechanically assist breathing by delivering air to the lungs. Many people may be familiar with ventilators in the hospital setting, such as the ICU, where large complex machines are used to assist with breathing. Modern ventilators, however, are lightweight and portable. They can be mounted on wheeled stands or battery or jet packs on a ventilator stand. Most of these operate on household electric current, or have internal batteries, and are operable with manual assistance. It is advisable to have a backup battery or even a generator readily available in case of power outages or emergencies.

How does mechanical ventilation work?
The diaphragm is the primary muscle for inspiration, along with the intercostal muscles between the ribs. Other muscles of the chest, neck, and shoulders play a smaller role. When these breathing muscles are weakened or paralyzed, mechanical ventilation is used to assist with breathing. A ventilator delivers a fixed volume of air over the rest of breathing complete or more breathing easier by assisting weakened respiratory muscles.

The muscles of this abdomen are important for breathing out and for an effective cough. Chest expansion muscles need to be exercised and maintained. To maintain a healthy condition, the diaphragm relaxes to its resting position. The work of breathing can be reduced by the use of external devices such as long-acting bronchodilators, respiratory exercise programs and mechanical devices such as the CoughAide.

What did mechanical ventilation develop?
The term "mechanical ventilation" refers to the use of either non-invasive or invasive ventilators, and one of the earliest forms was the use of external resuscitation. In the early 1900s, machines made use of the human lung, while the 1930s saw widespread use of mechanical ventilators for patients, particularly during the polio epidemics.

Positive pressure ventilators developed as a more effective breathing option to replace the older, sheltered pressure devices. Since the 1960s, computer technology has enabled manufacturers to produce even smaller, lightweight ventilators that are easier to transport and operate, and are better suited for people living at home.

What is negative pressure ventilation?
When the pressure around the chest is negative, it pushes the blood forward in the arteries and veins. The lungs expand the whole body, except the head. Any pressure changes between the chest and the thoracic duct of the lung is still used for a small number of people.

Other forms of negative pressure ventilation, also known as body ventilators, include the chest wall or chest, lung-inflated and intercostal. This Pneumotor™ is a smaller and more mobile version of the far lung that is still used for a small number of people.

A technologically advanced form of negative pressure ventilation called the Biotrace monitor, ventilator (BTT) monitors the thoracic or water-resistant phase of breathing. Higher frequencies and tidal volumes allow for higher rates of ventilation. The follow-up equipment specifications are for negative pressure ventilators currently on the market. There is no "standard" form for specification, and manufacturers are currently testing new forms of ventilation that may provide better outcomes. At this time, no data exists to support the use of the new systems.
What is Independent Living?
A personal definition by Adolf Ratzka, PhD

Independent Living is a philosophy and a movement of people with disabilities who work for self-determination, equal opportunities and self-respect.

Independent Living does not mean that we want to do everything by ourselves and do not need anybody or that we want to live in isolation.
Independent Living means that we demand the same choices and control in our everyday lives that our non-disabled brothers and sisters, neighbors and friends take for granted. We want to grow up in our families, go to the neighborhood school, use the same bus as our neighbors, work in jobs that are in line with our education and interests, and start families of our own.

Since we are the best experts on our needs, we need to show the solutions we want, need to be in charge of our lives, think and speak for ourselves – just as everybody else.
Section 504 of the Rehabilitation Act of 1974

No individual with a disability solely by reason of her or his disability, be excluded ... be subjected to discrimination under any program or activity receiving Federal financial assistance....

Public Law 94-142 (Education of All Handicapped Children Act) in 1975

Now codified as IDEA (Individuals with Disabilities Education Act) stated that to receive federal funds, states must develop and implement policies that assure a free appropriate public education (FAPE) to all children with disabilities.
Ventilator Users Can Survive the System with Your Help

* Utilize IVUN
* Listen to your patients
* Advocate with your patients
* Importance of your team
PETO Falstaff! (pulls back the arras) Fast asleep behind the arras, and snorting like a horse.

PRINCE HENRY Listen, how heavily he breathes! Look in his pockets.
"Chronic critical illness is a nebulous term for the condition of 5 to 10% of patients who survive a catastrophic illness or surgical procedure but are left with a prolonged (by one definition, longer than 21 days) need for mechanical ventilation. These patients tend to have recurrent infections, organ dysfunction, profound weakness, and delirium. At least half are dead within 1 year. Among those who survive, readmission rates are high, most remain institutionalized, and less than 12% are at home and functionally independent 1 year after their acute illness. The cost to the health care system is astronomical - more than $20 billion annually."  

Understanding Chronic Obstructive Pulmonary Disease (COPD): Part I

By Zach Gant, RRT, Director of Clinical Programs, and Greg Williams, RRT, Respiratory Therapy Manager, Alana HealthCare, Nashville, Tennessee.

COPD is a term used to describe two primary disease states: chronic bronchitis and emphysema. Each of these disease types has distinct characteristics and related symptoms, but many people can have a combination of the two.

**What exactly is COPD?**

COPD is chronic obstructive pulmonary disease.

**Chronic Bronchitis**

Chronic bronchitis is defined as a chronic productive cough lasting for a minimum of three months at a time, occurring year-round. The diagnosis must be made for a patient in whom other causes of a productive cough—e.g., pneumonia, heart failure, or gastroesophageal reflux disease—are excluded. Chronic bronchitis can be a difficult problem to treat, usually requiring long-term continuous treatment.

**Chronic Emphysema**

Chronic emphysema is a chronic lung disease characterized by abnormal, permanent dilation of the air spaces beyond the terminal bronchioles. The destruction of lung tissue results in decreased amount of gas exchange.
The Iconic Iron Lung and Polio Survivors in the USA
Jean L. Hoodley, PhD, Executive Director, St. Louis, Missouri

PHI is frequently asked how many iron lungs are still in use. Respiratory Colorado reports renting iron lungs to three individuals and providing parts and service to four other patients who own their device. All of these iron lungs were made by the J.H. Emerson Company, Cambridge, Massachusetts. However, the history of ownership and maintenance of the iron lung used by the majority of polio survivors in the United States is complex and warrants recording, using the PHI archives.

Point of reference: A brochure revised in June 1948 (seventh printing) entitled Respirators: Locations and Owners published by the National Foundation for Infantile Paralysis (NFIP), Paul O’Dwyer, president of NFIP, explains in the introduction that it is a list of the adult cylinder type respirators or “iron lungs.” The list totals 1,291 in the contiguous 48 states plus Washington, DC, and Hawaii. Owners included hospitals, the U.S. Army, fire departments, chapters of the NFIP, American Legion and other service groups, county medical societies and individual physicians and local citizens.

A timeline can move us a bit forward from the end of the story.

1968
Janice C. Campbell, a graduate of the University of Colorado, worked for the IBR Data Processing Division for 11 years before she started LIFE CARE International, Inc. He was the Chairman and CEO of the private company from April 1968 to October 1968. The company designed, manufactured, distributed and serviced the successful P5300 (1968) and P5400 (1969) volume ventilators, among other devices.

1969
LIFE CARE became a dealer of products for the Puritan Bennett, Emerson, Monaghan and Thompson Inspiration companies. The company then entered into a contract with the March of Dimes to maintain, for a monthly fee, respiratory equipment provided by the March of Dimes to the surviving polio population. The respiratory equipment (e.g., the Monaghan 706-7, Thompson Rapid and Marathon, Huxley, etc.) was scattered around the country in "equipment rental pools."

Survivors received letters telling them of their switch in working directly with the March of Dimes to LIFE CARE. A March 5, 1969, letter from the Metropolitan Chicago Chapter of the March of Dimes says, "So you understand how, with public support of the March of Dimes has markedly decreased since the success of the Salk and Sabin vaccines. It further explains that "It is necessary to consider other available resources" and suggests "...it is possible that you may qualify for assistance with this expense through the Medical Assistance Program, which is financed jointly by the State of Illinois and the Federal Government."

Some survivors thought that the equipment they received from the March of Dimes was "their property," and they were outraged when another entity became involved.

1970
J.H. Emerson stopped manufacturing their model of iron lung. The prototype was made in 1952. The exact number manufactured is not readily known but thousands were manufactured, "with limited production during the 1960s," according to a May 2004 company letter.

Department of Health and Human Services
OFFICE OF INSPECTOR GENERAL

Respiratory Assist Devices
With Back-up Rate

JUNE 2001
OIE-02-00410

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When I was about 6 years old, I had the polio virus. My right side was partially paralyzed, including the ability to swallow easily.

Recently, I was diagnosed, after two hospital stays, with bacterial pneumonia, COPD and a paralyzed diaphragm on my right side. The pneumonia is cleared up. The COPD appears to be minor (for now). However, I will have the paralyzed diaphragm for the rest of my life. I must sleep sitting up and as you can imagine, all activities are difficult.

I also have been diagnosed with neuropathy and restless legs. I am on gabapentin and pramipexole for these issues.
The info was very useful. I just had a sleep test last night and will have a pulmonary function test in a few weeks. My pulmonary specialist will then determine the course of action. I find conflicting info among the post-polio documentation. Some advocate oxygen and some PLV-100 volumizer. Right now my doctor has me on oxygen. I am trying to stay off oxygen during day to live a more productive life and only use it at night.

The technician at the sleep study last night said my sats were at 76% while asleep, and put me on oxygen right away. She also forced me to try to sleep on my side as I was cutting off my air passage every time my head bobbed to sleep while sitting up.
I still can't sleep on my back, but the side is progress. As it should be, because it has been two months since diagnosis of pneumonia, so I should be getting better at least in my left lung.

Lots of controversy regarding surgery, as well. If you can't breathe well, you can't be put under...so, to make a long story short, I am thrilled with the info you sent and will continue to update you on my progress. When I see the doctor, I will have a list of questions based on the documentation you sent me. I am determined to lead the best life I can, so I will continue to look for answers.
Because of the complexity of the medical/physical care and time it consumes, the psychological issues (loneliness, anger, anxiety, depression) of ventilator users are not addressed adequately. The importance of forming a good team is critical to insuring that ventilator users can survive the system.
www.ventusers.org  •  info@ventusers.org

Email info@ventusers.org to be placed on the mailing list.