
More Personal Perspectives

"Learning to lead as quality a life as I did before the ventilator was just another challenge to overcome I seem to have done more since the tracheostomy and ventilator than ever."
Lori Hinderer, USA

"I want to say how pleased I am that *I.V.U.N. News* exists, to know that many more people live with ventilation and manage their lives as good as possible, with their ups and downs."
Daniel Vilaseca Dreischer, Spain

"As a polio survivor who graduated from the iron lung, I would encourage anyone to try night-time nasal ventilation. Once I quit fighting and accepted the ventilator, it began working."
Vera Overholt, USA

"In July, 1975, I had a tracheostomy and I have been a permanent respirator user ever since. I live in my own apartment with round-the-clock help. I employ six helpers, each working consecutive 24 hours per week and taking turns about weekends and holidays."
Bente Madsen, Denmark

"As a respiratory polio survivor who has used an iron lung for 15 years, I am once more in control of my own life with the use of a positive pressure mask."
Marsha Ballard, USA

I.V.U.N. Publications

I.V.U.N. News.
USA: consumer, \$8; others \$20.
Canada, Mexico, overseas surface:
consumer, \$10; others, \$22.
Overseas air: consumer, \$12; others \$24.
Send for a free back copy or send a SASE for the latest I.V.U.N. Directory.

Ventilators and Muscular Dystrophy, edited by Nancy Schock, MA, and Agatha Colbert, MD, 1987. A 36-page handbook examining the options of mechanical ventilation for individuals with Duchenne muscular dystrophy and their families.
Price - USA: \$6 postpaid; others \$7.35

Directory of Sources for Ventilation Face Masks, edited by Bud Blitzer, 1991. A 12-page resource listing sources for oral and nasal face masks.
Price - USA: \$2.50 postpaid; others \$4.

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

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Coordinated by
Gazette International
Networking Institute
(G.I.N.I.)

International

Ventilator

Users

Network

(I.V.U.N.)

Advocates for home care
and longterm ventilation

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Mechanical Ventilation and Home Care

The 1950s polio epidemics led to the development of ventilator technology and to new ideas about health care. It was soon realized that respiratory polio survivors were unnecessarily occupying expensive hospital beds when they could be cared for at home with attendants, equipment maintenance, and other support services for one-third of the hospital cost.

Thus, respiratory polio survivors were sent home with a variety of breathing aids (iron lung, cuirass, or rocking bed). They pursued their educations and careers, married and raised families, traveled, and contributed to their communities. As the years went by, these now longterm ventilator users helped refine ventilator equipment in size, portability, operation, and cost.

These developments, coupled with increasing recognition of the cost benefits of home care, enable individuals with high spinal cord injuries, ALS, muscular dystrophy, cystic fibrosis, and technology-assisted infants and children to live at home in their communities, rather than in an institution.

Today, advances in positive pressure ventilation and noninvasive forms of ventilation, such as the face mask, have increased the independence and quality of life of longterm ventilator users while at the same time decreased the need for unnecessary tracheostomies.

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

I.V.U.N. is a worldwide network of ventilator users and health professionals experienced in and committed to home care and longterm mechanical ventilation.

I.V.U.N. networks through *I.V.U.N. News*, a biannual newsletter, offering articles on family adjustments, equipment and techniques, travel, ethical issues, medical topics, and resources. Contributors include health professionals and, most important, the true experts - ventilator users themselves.

I.V.U.N. is a forum for ventilator users, pulmonologists, pediatricians, respiratory therapists, ventilator manufacturers and vendors to discuss unique problems of home ventilation and to cooperatively seek solutions.

I.V.U.N.'s Directory, published each Fall, lists longterm ventilator users and health professionals committed to home care and mechanical ventilation.

Philosophy

Although I.V.U.N.'s constituency includes health professionals as well as ventilator users, I.V.U.N. is the voice of consumers. I.V.U.N.'s goal is to foster a positive image of ventilators and to demystify their use. Ventilator use should appear as common and natural as

the use of eyeglasses or hearing aids or wheelchairs or any other technical aid that improves people's lives.

I.V.U.N. affirms the safety and cost benefits of longterm home care. The alternative of institutional placement is too often unnecessary and unwarranted.

Personal Perspectives

"Our son was suffering from chronic respiratory failure and would require continued mechanical ventilation, possibly for the rest of his life. . . . Life is different than I had once envisioned, but it is still good, it is still worth living for all of us."
Debbie Poehlmann, USA

"I am paralyzed from the shoulders down and use a PLV-100. I have an hour's free breathing time without it, and I know how to frog breathe. Currently, I am coaching wrestling and gymnastics, and counseling families of people with spinal cord injuries."
Randy Haims, USA

"It is almost two years since I left the hospital to live at home. It seems almost a miracle to have survived, having the most serious disability with a ventilator and living independently in the community."
Sato Kimiyo, Japan