



The following excerpt has been taken from the Christopher & Dana Reeve Foundation Paralysis Resource Center website.

<http://www.christopherreeve.org/site/c.mtKZKgMWKwG/b.4453421/k.9F9F/Respiratory.htm>

Respiratory, Ventilator and Trach Resources

As we breathe, oxygen in the air is brought into the lungs and into close contact with the blood, which absorbs it and carries it to all parts of the body. At the same time, the blood gives up carbon dioxide, which is carried out of the lungs with air breathed out.

Lungs are not affected by paralysis. However, the muscles of the chest, abdomen, and diaphragm can be affected. As the various breathing muscles contract, they allow the lungs to expand, which changes the pressure inside the chest so that air rushes into the lungs. This is inhaling – which requires muscle strength. As those same muscles relax, the air flows back out of your lungs, and you exhale.

If paralysis occurs at the C-3 level or higher, the phrenic nerve is no longer stimulated and therefore the diaphragm does not function. This means mechanical assistance -- usually a ventilator – will be needed to breathe.

Persons with paralysis at the mid-thoracic level and higher will have trouble taking a deep breath and exhaling forcefully. Because they don't have use of abdominal or intercostal muscles, these people have also lost the ability to forcefully cough. This can lead to lung congestion and respiratory infections.

Moreover, secretions can act as glue, causing the sides of your airways to stick together and not inflate properly. This is called atelectasis, or a collapse of part of the lung. Many people with paralysis are at risk for this. Some people have a harder time getting rid of any colds or respiratory infections and have what feels like a constant chest cold. Pneumonia is a possibility if secretions become the breeding ground for various bacteria.

A useful technique is the assisted cough: an assistant firmly pushing against the outside of the stomach and upwards, substituting for the abdominal muscle action that usually makes for a strong cough. This is much gentler than the Heimlich maneuver and it's important to coordinate pushes with natural breathing rhythms.

Another technique is percussion: this is basically a light drumming on the ribcage to help loosen up congestions in your lungs.

Postural drainage: This uses gravity to drain secretions from the bottom of your lungs up higher into your chest where one can either cough them up and out, or get them up high enough to swallow. This usually works when the head is lower than the feet for 15 or 20 minutes.

Ventilator users with tracheostomies need to have secretions suctioned from their lungs on a regular basis; this may be needed anywhere from every half hour to only once a day.

Ventilators

There are two basic types of mechanical ventilator. Negative pressure ventilators, such as the iron lung, create a vacuum around the outside of the chest, causing the chest to expand and suck air into the lungs. Positive pressure ventilators, which have been available since the 1940s, work on the opposite principle, by blowing air directly into the lungs.

A small face mask can also be used over the nose and/or the mouth for positive pressure ventilation. For patients who need breathing assistance only part of the time, such non-invasive means offer a way to avoid the complications associated with tracheostomies.

Another technique breathing involves the implantation of an electronic device in the chest to stimulate the phrenic nerve and send a regular signal to the diaphragm, causing it to contract and fill the lungs with air. Phrenic nerve pacers have been available since the late 1950s but are expensive and are not widely used.

Tracheostomy care

There are many potential complications related to tracheostomy tubes, including the inability to speak or swallow normally. Certain tracheostomy tubes are designed to direct air upward during exhalation and thus permit speech during regular, periodic intervals.

Another tracheostomy-associated complication is infection. The tube is a foreign body in the neck, and has the potential of introducing organisms that would ordinarily be stopped by natural defense mechanisms in the nose and mouth. Cleaning and dressing of the tracheostomy site on a daily basis is an important preventive measure.

Sources: Craig Hospital, University of Miami School of Medicine, University of Washington School of Medicine/Department of Rehabilitation Medicine.

Websites

<http://www.ventusers.org/index.html>

International Ventilator Users Network (IVUN)

4207 Lindell Boulevard, #110

Saint Louis, MO 63108-2930

Phone: 314-534-0475

E-mail: info@ventusers.org

IVUN, a resource for people who use ventilators, includes a newsletter and articles by health care professionals and venturesome vent users. The organization's mission is to enhance the lives and independence of home ventilator users and polio survivors through education, advocacy, research and networking.

<http://www.craighospital.org/SCI/METS/breathing.asp>

Craig Hospital: The Art of Breathing

This article discusses how spinal cord injury survivors can prevent breathing problems. It first appeared in the April 2001 issue of *Paraplegia News*.

<http://www.doctorbach.com/center.htm>

Center for Noninvasive Mechanical Ventilation Alternatives and Pulmonary Rehabilitation

The Center for Noninvasive Mechanical Ventilation Alternatives and Pulmonary Rehabilitation says it has removed over 100 tracheostomy tubes from ventilator users with no ability to breathe and taught many of them how to breathe without ventilators.

<http://calder.med.miami.edu/pointis/sciman.html>

University of Miami School of Medicine Rehab Team Site: Spinal Cord Injury Manual for Patients and Families

The University of Miami's School of Medicine's Point of Care, Team-based Information System (PoinTIS) website provides comprehensive information on spinal cord injury and traumatic brain injury rehabilitation for health care providers, patients and patients families. Selecting *Respiratory Management* on the left side will bring up articles on breathing and respiratory tract complications and treatments.

<http://www.ventworld.com/>

VentWorld.com

VentWorld.com offers ventilator product and supplier information, news, discussion, education, tools, and vent resources for the respiratory and critical care community.

<http://www.makoa.org/vent/index.html>

Vent Users' Support Page

This website includes links to articles on respiratory management, product vendors, and more. There is also a mailing list people can join.

<http://www.lincare.com/>

Lincare

Lincare provides respiratory care, infusion therapy and medical equipment to patients in the home.

<http://www.tracheostomy.com/>

Aaron's Tracheostomy Page

This site's mission is to provide information on tracheostomy and to facilitate parent-to-parent networking and support. There is a lot of information on pediatric trach care and links to other resources, including listservs on adult and pediatric tracheostomies.

<http://www.doctorbach.com>

Dr. John Bach

Dr. Bach specializes in noninvasive ventilation for those with Duchenne muscular dystrophy, ALS, and spinal muscular atrophy.

<http://ajrccm.atsjournals.org/content/161/1/297.full>

American Journal of Respiratory and Critical Care Medicine: Care of the Child with a Chronic Tracheostomy

This Official Statement of the American Thoracic Society was adopted by the ATS Board of Directors in July 1999. It covers tracheostomy tube selection, tracheostomy tube care, suctioning, humidification, speech development, caregiver education, medications, monitoring, decannulation procedures, complications, and areas of suggested research.

<http://www.synapsebiomedical.com/products/neurx.shtml>

Synapse: NeuRx Diaphragm Pacing System

E-mail: info@synapsebiomedical.com

A breathing pacemaker approved by the FDA in June 2008 for use in certain spinal cord injured, vent-dependent persons. The site has patient information on the system and lists treatment centers and model spine centers in the U.S.

Online Discussion Groups

<http://www.tracheostomy.com/>

Aaron's Tracheostomy Message Boards

The message boards include forums on pediatric and adult tracheostomies and can be accessed by clicking on the *Networking* tab or by going directly to

<http://www.tracheostomy.com/forum/index.php>.

<http://www.tracheostomy.com/networking/listserv.htm>

Trachties Listserv

Trachties is a place for networking, sharing of ideas and resources for dealing with life with a tracheostomy. It is open to individuals with tracheostomies, friends and caretakers of kids or adults with tracheostomies.

Newsletters

<http://www.ventusers.org/edu/valnews/index.html>

Ventilator-Assisted Living

This bi-monthly newsletter (sent electronically) from Post Polio Health International, links ventilator users, their families and peers with each other and with health professionals committed to home mechanical ventilation. Articles include such topics as family adjustments, equipment and techniques, medical issues, travel and ethical issues.

Pamphlets

Information about Ventilator-Assisted Living. St. Louis, MO: Post-Polio Health International, 2003.

This 10-page pamphlet is available for free by calling 314-534-0475.

<http://patients.thoracic.org/information-series/en/resources/use-of-a-tracheostomy-with-a-child.pdf>

American Thoracic Society: Use of a Tracheostomy with a Child

This 2-page pamphlet answers common questions parents have about tracheostomies and offers tips for avoiding complications.

<http://patients.thoracic.org/information-series/en/resources/mechanical-ventilation.pdf>

American Thoracic Society: Mechanical Ventilation

This 2-page pamphlet answers common questions about ventilators and their use.

Videos

<http://www.spinalcord.uab.edu/show.asp?durki=97417>

Spinal Cord Injury Information Network: Secondary Conditions of Spinal Cord Injury Health Education Video Series (18 minutes)

The Respiratory Management video can be streamed online or downloaded. It covers signs, symptoms and general treatment options of potentially life-threatening conditions and discusses self-care issues such as smoking cessation, congestion, vaccinations (influenza and pneumonia), and weight management.

The following books and videos are available for free loan from the PRC library. For more information, please see www.paralysis.org and click *Borrow from Our Lending Library* under PRC Quick Links.

Books

- Bach, John R., M.D. **Noninvasive Mechanical Ventilation.** Philadelphia: Hanley & Belfus, 2002.

- Presents noninvasive ventilation as an alternative to tracheostomy. It prolongs survival while decreasing the risk of pulmonary complications, hospitalizations, and costs.
- Bissell, Cynthia M. **Pediatric Tracheostomy Home Care Guide**. Grafton, MA: Twin Enterprises, Inc., 2000.
Written by the mother of a child with a tracheostomy who is also a nurse. Clear pictures and explanations of procedures and equipment.
 - Gilgoff, Irene S. **Breath of Life: The Role of the Ventilator in Managing Life-Threatening Illnesses**. Lanham, MD: Scarecrow Press, 2001.
Explores the pros and cons of mechanical ventilation for Duchenne Muscular Dystrophy and other patients suffering from restricted breathing.
 - **IVUN Resource Directory**. (International Ventilator Users Network) St. Louis, MO: Gazette International Networking Institute (GINI). 2002. Available in print or online (for free at <http://www.post-polio.org/ivun/d.html>)
A directory of equipment manufacturers and doctors who specialize in ventilation as well as a contact list of patients on ventilators.
 - Johnson, Dawn L. et al. **Ventilator-Assisted Patient Care : Planning for Hospital Discharge and Home Care**. Rockville, MD: Aspen Publishers, 1986.
Written for healthcare professionals to facilitate discharge planning of vent-dependent persons.
 - Kertoy, Marilyn. **Children with Tracheostomies Resource Guide**. Albany, NY: Singular/Thomson Learning, 2002.
Written for speech-language pathologists.
 - Kitchen, Julie A. et al. **Life Care Planning for the Ventilator Dependent Patient: A Step-by-Step Guide**. Orlando, FL: Paul M. Deutsch Press, 1990.
 - Pierce, Lynelle N.B. **Management of the Mechanically Ventilated Patient**. St. Louis, MO: Saunders Elsevier, 2007. 2nd edition.
Written for health care professionals.
 - **Respiratory Management Following Spinal Cord Injury: A Clinical Practice Guideline for Health-Care Professionals**. Consortium for Spinal Cord Medicine. Washington, DC: Paralyzed Veterans of America, 2005. Available for free download. Go to www.pva.org, click on *Publications* at the top, then click on *Guidelines and Publications* on the left, then click *Download CPGs and Consumer Guides*, and then click *Consumer Guides*.
 - Wolgin, Francie. **Advanced Skills and Competency Assessment for Caregivers Vol. 1**. Upper Saddle River, NJ: Brady/Prentice-Hall, 1998.

A skill book for nurses and other health care practitioners. Includes a section on Tracheostomy Care.

- **The Ventilator-Assisted Child: A Practical Resource Guide.** San Antonio, TX: Communication Skill Builders, 1997.
Covers a wide variety of topics including chapters on teenagers on vents, sexuality for vent-dependent teens, camps, recreation, role of nursing, physical therapy.

Videos

- **Breathing Easy: Children on Ventilators at School.** Distributed by Learner Managed Designs Inc. (30 minutes)
This video illustrates how children assisted by ventilators can be successfully integrated into school settings. Medical therapies and psychosocial support needed to ensure that a student using a ventilator is an active participant in the classroom are described.
- **Breathing Lessons: The Life and Work of Mark O'Brien.** Fanlight Productions, 1996. (35 minutes).
An Academy Award winner for Best Short Documentary. Covers O'Brien's life in an iron lung.
- **Home Tracheostomy Care for Infants and Young Children .**University of Colorado Health Sciences Center. 2000. Distributed by Learner Managed Designs Inc.
This video covers the spectrum of home care needs for a child with a tracheostomy, including changing the trach tube, tying techniques, suctioning and accidental decanulation. Information on speech and feeding in connection with tracheostomies is also provided. Also available in Spanish.
- **Managing the Mechanically Ventilated Patient: Endotracheal Tubes/Chest Tubes/ Aerosols.** American Association for Respiratory Care, 1997.
- **Mechanical Ventilation: Made Really Easy.** New York: NUSA Inc, 2000.
- **Ventilation: The Decision Making Process (for ALS Patients, Their Families, and Their Friends).** The Les Turner ALS Foundation in Skokie, IL. Phone: 847-679-3311.

The information contained in this message is presented for the purpose of educating and informing you about paralysis and its effects. Nothing contained in this message should be construed nor is intended to be used for medical diagnosis or treatment. It should not be used in place of the advice of your physician or other qualified health care provider. Should you have any health care related questions, please call or see

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