

# **VENTILATORS:**

## **Alternatives For**

### **Long-Term and Home Use**

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**\* A MANUAL FOR PEOPLE WHO ARE CONSIDERING  
THE LONG TERM USE OF A VENTILATOR AT HOME.**

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# Ventilators: Alternatives for Long-term & Home Use.

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Additional copies of this manual may be obtained by contacting the authors. It is expected that the manual will be updated during the next year to include additional information. Please send suggestions or comments so that the manual can be improved to meet the needs of both health care professionals, and people who might use a mechanical ventilator for long-term or home use.

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The major goal of this manual is to help patients, physicians and other health care professionals as they consider using mechanical ventilation for *long-term care and use at home*. It is for people who may require a method to support their breathing because of long-term respiratory failure. The manual presents an overview of the many different ways to use mechanical ventilation to assist breathing: providing a showcase of alternatives to assist the patient and their family, as well as the health care professional team. For further information additional sources are noted at the end of the manual, as well as illustrative equipment.

There are many methods to consider for assisting breathing. Each person's medical condition needs careful assessment. A physician should advise you which of these options might be best for you (mark these pages with a paperclip), and the pros and cons of each. Not all can be considered for each person. And, if a disease progresses, the best method may change. You need to work closely with your physician.

Some physicians and medical centers have had considerable experience with home mechanical ventilation and techniques of preparing people to do this successfully. Sometimes there is little experience with home mechanical ventilation, or only experience with one method of ventilation, such as via tracheostomy. You should be aware of this in order to obtain enough information and advice.

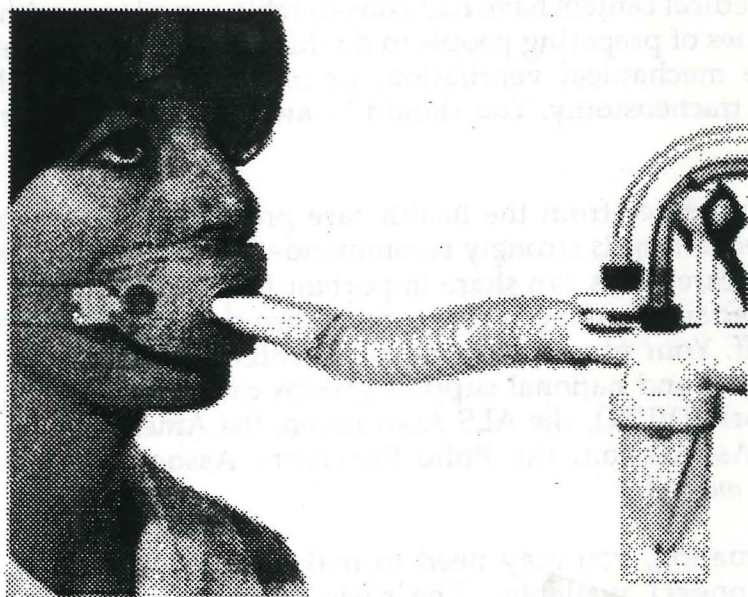
In addition to receiving advice from the health care professional team, advice from other *people who use a ventilator at home* is strongly recommended. Both the ventilator user and their family, friends or other caregivers can share important information about their experiences. This helps with initial decision making. These contacts are also useful later on if you choose to use a ventilator yourself. Your physician or medical center can often help you contact other families. In addition local and national support groups can help, such as: the International Ventilator Users Network (IVUN), the ALS Association, the American Lung Association, the Muscular Dystrophy Association, the Polio Survivors Association, etc... *See the list of organizations at end of the manual.*

Depending on your situation, you may need to make decisions quickly, *or* there may be weeks or months (or longer) available. The basic decision to use a ventilator to assist breathing, if respiratory failure develops, is often closely tied to your understanding of the options, ...their feasibility, benefits and burdens. Therefore we advise serious review of the information now. Do not put it off. Decision making is often a sequential process, as you become more familiar with the information as well as your own condition. However, dodging the issues may result in critical events occurring before you are ready. Then the outcomes may be dictated by a series of emergency events, or an avoidable complication, rather than your preferences. The time to make a decision is before you need it.

*Elective trials:* It is sometimes possible to try one or more of the noninvasive alternatives listed in the manual at home, to get some hands-on experience, before severe long-term respiratory failure occurs. This may allow skills to develop, and sometimes will help you select the preferred equipment. You may also learn whether you, and your family, really want to use a ventilator at home. It will require some patience to learn and adapt to this type of equipment. When successful, it can provide the needed ventilation assistance for many years, and may allow a person to carry on with other activities without being limited to the home. Elective trials may be more useful for people with neuromuscular conditions, and possibly less useful for people with COPD or other obstructive airways diseases. Any ventilator system needs to be given a period of trial use before making a decision regarding its long-term use.

...and other health care professionals should be consulted for long-term and short-term...  
...to support their breathing because of long-term...  
...an overview of the many different ways to use...  
...providing a thorough understanding of alternatives to assist the...  
...well as the health care professional team. For further information...  
...of the material as well as illustrative equipment...

...to think in terms of assisting breathing. Each person's needs and condition...  
...A physician should advise you which of these options might be best...  
...a page with a paragraph and the pros and cons of each. This will...  
...And if a device is prescribed, the best method may change. You...  
...work closely with your physician.



**BENNETT LIPSEAL® MOUTHPIECE**

...is sometimes possible...  
...to get some...  
...before...  
...will...  
...to use a...  
...to this type of equipment...  
...for many years and may...  
...to the...  
...and possibly...  
...when...  
...for your...

The different alternatives for long-term mechanical ventilation follow in the next sections. You can review them all. However, we suggest that you start by picking out those most likely to be useful to you. Your physician should advise you which ones would be likely to be best for you. Mark these pages with a paperclip for easy review.

It is usual for people who have never needed a ventilator before to have considerable fear and anxiety. The decision to use a ventilator is seldom easy, and most people resist it. Talking to a lifelong ventilator user can be very helpful since many are high achievers, make a good income, and are prominent in their field of work. Ventilator users are usually enthusiastic, and are often able to provide some continuing support. And, life is very satisfying for them. The major challenge frequently reported is finding and coordinating the necessary resources.

### Noninvasive Ventilation (NIV):

We encourage the use of noninvasive ventilation (NIV) whenever this is possible. It is easier to arrange and take care of; has fewer complications; often involves less over-all cost; and requires less skilled assistance. NIV has been successful for people with neuromuscular disease, and also for people with COPD. It is easier to use when started early, electively, before a ventilator is needed most of the 24 hours. NIV can sometimes be started after acute care in the hospital intensive care unit (ICU); after endotracheal intubation, as an alternative to tracheostomy. However many medical centers have less experience with NIV, than with tracheostomy methods of ventilator support. It is much easier to try NIV, than tracheostomy IPPV, when you are still trying to make a decision. The factors that favor NIV include:

- The ability to cough effectively, and clear secretions.
- Aspiration of food or saliva is not a major problem.
- It is possible to communicate effectively.
- It is possible to breathe without the ventilator for an hour at a time, particularly if this can be done for more than several hours at a time. However there are some people using NIV who are almost completely ventilator dependent 24 hours per day.
- Age: NIV has been used successfully by adults of all ages, and even children age two years or more.

If noninvasive ventilation (NIV) might work for you, *the most frequently used methods to review first are:* mouth or nasal intermittent positive pressure ventilation; chest cuirass negative pressure ventilation; or the pneumobelt.

### Tracheostomy Intermittent Positive Pressure Ventilation (TIPPV):

Tracheostomy has been the most frequently used method for long-term ventilation in the United States. It is most likely to be needed when:

- Noninvasive ventilation is not successful.
- Cough is ineffective, and there are considerable secretions or aspiration problems.
- A ventilator is required for 22 to 24 hours per day, with little ability to breathe independently.
- For infants and very young children.

**TABLE 1.**

**Characteristics that Favor Home Mechanical Ventilation (HMV)**

- ❖ A person highly motivated and engaged in living.
- ❖ Medical problems are stable or progressing slowly.
- ❖ Independent function allows some activities of daily living.
- ❖ Good ability to communicate and direct the care needed.
- ❖ The person and family understand the options, the pros and cons.
- ❖ The family is able to and wants to participate in HMV if needed.
- ❖ Resources for equipment and caregivers are available.
- ❖ An experienced multi-disciplinary team supports HMV.

**TABLE 2.**

**Characteristics that Discourage Home Mechanical Ventilation (HMV)**

- ❖ Disability is advanced when respiratory failure occurs.
- ❖ Communication ability is very limited.
- ❖ Interest or motivation to continue living is low.
- ❖ The person is not mentally alert or self-directed.
- ❖ Caregiver support is not available from family or friends.
- ❖ Resources needed for HMV are not available.
- ❖ Health care professionals have little experience with HMV.

## "Its Your Choice"

### Essential Points for Patients and their Families:

Making an informed decision about whether to use a ventilator requires time, thought, and careful evaluation of the facts. In order to have choice you must have good information. You should know...

- ❖ Your condition and prognosis.
- ❖ Your options — and the pros and cons of each.
- ❖ The resources you will need for each alternative.
- ❖ Which resources are available to you: financial and psychosocial.
- ❖ People and families who can share their experience with you.
- ❖ The impact each alternative will have on both you *and* your family.  
Your family need to be partners in decision making.
- ❖ Information about decision making, advance directives, proxy decision making, and other ways you can ensure that your decisions will be known, and that your wishes will be carried out. *And...*
- ❖ Whether a trial using some equipment at home might be useful.

Once you have gathered the information you need, and have evaluated the resources available to you, you should develop a plan:

- ◆ Include your family, and other people who are important to you, in your decision making process.
- ◆ Seek advice from professionals who *have experience working with people who use a ventilator at home.*
- ◆ Consider whether using some equipment at home on a trial basis might be helpful.
- ◆ Do a careful evaluation — don't base your decision on initial emotional reactions.
- ◆ Avoid denial and procrastination.
- ◆ Talk to other people with similar medical problems who are using a ventilator at home or have already tried options you are considering... Such people, and their families, can often provide the best information.

*Remember*, other people like you already have experience with this. Be sure to talk to them because they can often provide the best information. ...It's *your* choice: make your decision an informed and thoughtful one. — The one that's best for you.

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The video "*Its Your Choice*" is helpful to use in conjunction with this manual. It may be obtained from Valona Productions, 14621 Titus Street #108, Van Nuys, CA 91402. (818) 785-9982. For a copy, send your request with a check for \$20. The video was produced in 1992 by Ismail Tsieprati, a ventilator user, and his wife Cheryl Tsieprati.



# Coordination of Care/ Case Management

*There is a remarkable array of goods and services available for the home care patient. The term "case management" has evolved to include those activities necessary to determine the patient's needs, arrange for and coordinate the appropriate services, and to monitor the effectiveness of services and reassess them as needed.*

In the ideal, the goal of all health care is patient independence in self-care, *ie*, the patient becomes his or her own "case manager." When the patient's health problems worsen and the patient becomes dependent on others, assistance with case management decision making may be necessary. The levels of case management are as follows:

- The patient is his or her own case manager
- The patient needs assistance from family members or significant others for planning/coordinating care
- If problems are too complex for the family to deal with, patient/family/professional team must coordinate care
- For the most complex levels of care, a multi-disciplinary professional team is needed to assist the patient and family. *Such a team should have a designated case manager/team leader.*
- Flexibility is needed to move between levels of case management with the ultimate goal of patient independence and continuity of care.

Surveys indicate that 80% of patients requiring care in their home receive all their needed assistance from family and friends. The physician may be the only health professional who provides care and advice in these cases.

- Most patients and families turn to their physician for advice when they perceive the need for additional resources
- Physicians are a crucial link to community resources
- Physicians need to become familiar with the one or two telephone numbers they need to access community resources

**From: Physicians and Home Care. Guidelines for the Medical Management of the Home Care Patient. American Medical Association. (1992) Chicago, IL. 23 pages.**

### Acknowledgements

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*This manual is dedicated to children, adults and their families who are facing the possibility of needing mechanical ventilation. Our goal is to better prepare people and their physicians for the critical choices related to the long-term and home use of a ventilator.*

E.A.O.  
A.S.B.

TABLE 3.

**Some Nasal Masks, Face Masks and Mouthpieces:**

<i>Company:</i>	<i>Comments:</i>	
ADAM nasal pillows	Puritan-Bennett	fits into nose directly
Bennett Seal Mouthpiece	Puritan-Bennett	plain mouthpiece can also be used
Companion Nasal Mask	Puritan-Bennett	
Contour Nasal Mask	Respironics Inc.	
CPAP Nasal Mask	Healthdyne Technologies	
CPAP nasal seal mask	Healthdyne Technologies	fits into nose directly
Custom Mask	LIFECARE	custom molded mask
Integral Custom Mask	SEFAM & LIFECARE	custom molded mask
Mouthpiece ± mouthseal	LIFECARE	
Nasal mask	Atomisor	fits into nose directly
Remmer Mask	REMAFA Tech	custom molded mask
SEFAM Nasal+ mask	SEFAM	
Softwear™ Nasal Mask	LIFECARE	
Sullivan™ Nasal Mask	ResCare	bubble cushion design
Thermoformable (Lyon) Custom Mask	SEFAM & LIFECARE	custom molded mask

TABLE 4.

**Some Portable Ventilators used for Home Use:**

<i>Company:</i>	<i>Model:</i>	<i>Comments:</i>
Aequitron Medical Inc. [USA]	LP-10 and LP-6 plus	
Bear Medical Systems, Inc. [USA]	Bear 33	
Breas Medical AB [Sw]	PV 501	
Dräger Medical S.A. [Fr]	EV 800	
LIFECARE [USA]	PLV-100** & PLV 102	
LIFECARE [USA]	NEV-100	negative pressure ventilator
Monaghan Medical Corp. [USA]	179-C	negative pressure ventilator
PneuPAC Limited [UK]	BromptonPAC	for mask applied ventilation
Puritan-Bennett [USA]	Companion® 2800 & 2801	
Puritan-Bennett [USA]	Companion® 2500**	
Puritan-Bennett [USA]	MV Maxivent	negative/positive pressure
Respironics Inc. [USA]	BiPAP® S/T	for mask applied ventilation
SEFAM [Fr]	VENTIL+	for mask applied ventilation
Taema [Fr]	Monal D & DCC	
Thomas Respiratory Systems [UK]	Nippy™	

\*\*These are examples of ventilators that can be used to operate a pneumobelt.  
Company location: [UK] England, [Fr] France, [Sw] Sweden, [USA] United States.

## Face, Mouth, or Nasal Intermittent Positive Pressure Ventilation

These techniques are being used more often in recently. A large variety of nasal and face masks, lip seals, and mouthpieces have been developed. These devices can even be used during sleep. They may be very useful for some people with neuromuscular or musculoskeletal disease or COPD. People who are more severely paralyzed may find that they can only use the device for a limited number of nights in succession and need to resort to alternative methods from time to time.

Mouth intermittent positive pressure ventilation (**mouth IPPV**) is a method of delivering air at a controlled amount of pressure through a mouthpiece held securely between the lips. It is most easily achieved with a simple mouthpiece, or with a Bennett Lipseal® mouthpiece which can be strapped to the person's mouth (specially if used at night). Other custom designed mouthpieces or orthotic devices can be made at some medical centers.

Nasal intermittent positive pressure ventilation (**nasal IPPV**) uses a specially designed nasal mask. Many types are now available including some which are custom fitted. Many nasal masks were developed for people with sleep apnea, who are helped by nasal continuous positive airway pressure (CPAP), and were then used or adapted for nasal IPPV. These methods offer the opportunity for noninvasive ventilation to many people who would otherwise need to use tracheostomy. Nasal IPPV is a major advance that is being used more often today as medical centers develop further experience with it, and as better nasal masks become available. It is usually necessary to try different masks to find one which is comfortable, avoids skin irritation, and allows effective ventilation without excessive leak of air. The technique requires some practice, and trial and error, before it can be regularly used. Some people combine daytime use of mouth IPPV with another method at night, such as a tank, or a nasal mask. A small portable ventilator is usually used, connected to the mask, to deliver a set volume of air, or pressure limited ventilation. The rate, number of breaths per minute, can be either controlled (set), or triggered by the person (assisted). If the "assist/control" mode is used, it is generally best to set the rate to that which is usually required in order to avoid the work of breathing to initiate each breath. The equipment is small and easily portable. Face, mouth or nasal IPPV may lead to gastric insufflation and distension; gastric aspiration is a potential problem. Some people have excessive oral/mouth air leakage during sleep. This can result in inadequate night-time ventilation. This may be improved by using chin straps. Checking is recommended to be sure nighttime ventilation is effective. A major problem with regular use of a mask may be discomfort or skin injury; both may often be avoided by proper mask selection. If there are problems, consider the Sullivan™ bubble cushion mask, a silicon custom molded mask, or other custom made orthotic device.

**Note:** [1] The Directory of Sources for Ventilation Face Masks, Bud Blitzer - Editor, a 16-page illustrated directory, is available from IVUN for \$2.50 post-paid. Send request with your check to: International Ventilator Users Network, 5100 Oakland Avenue, #206, Saint Louis, Missouri 63110.

[2] Custom Nasal Mask - Instruction Manual a 48 page manual showing the step by step process of creating a custom silicone nasal mask, is available from LIFECARE.

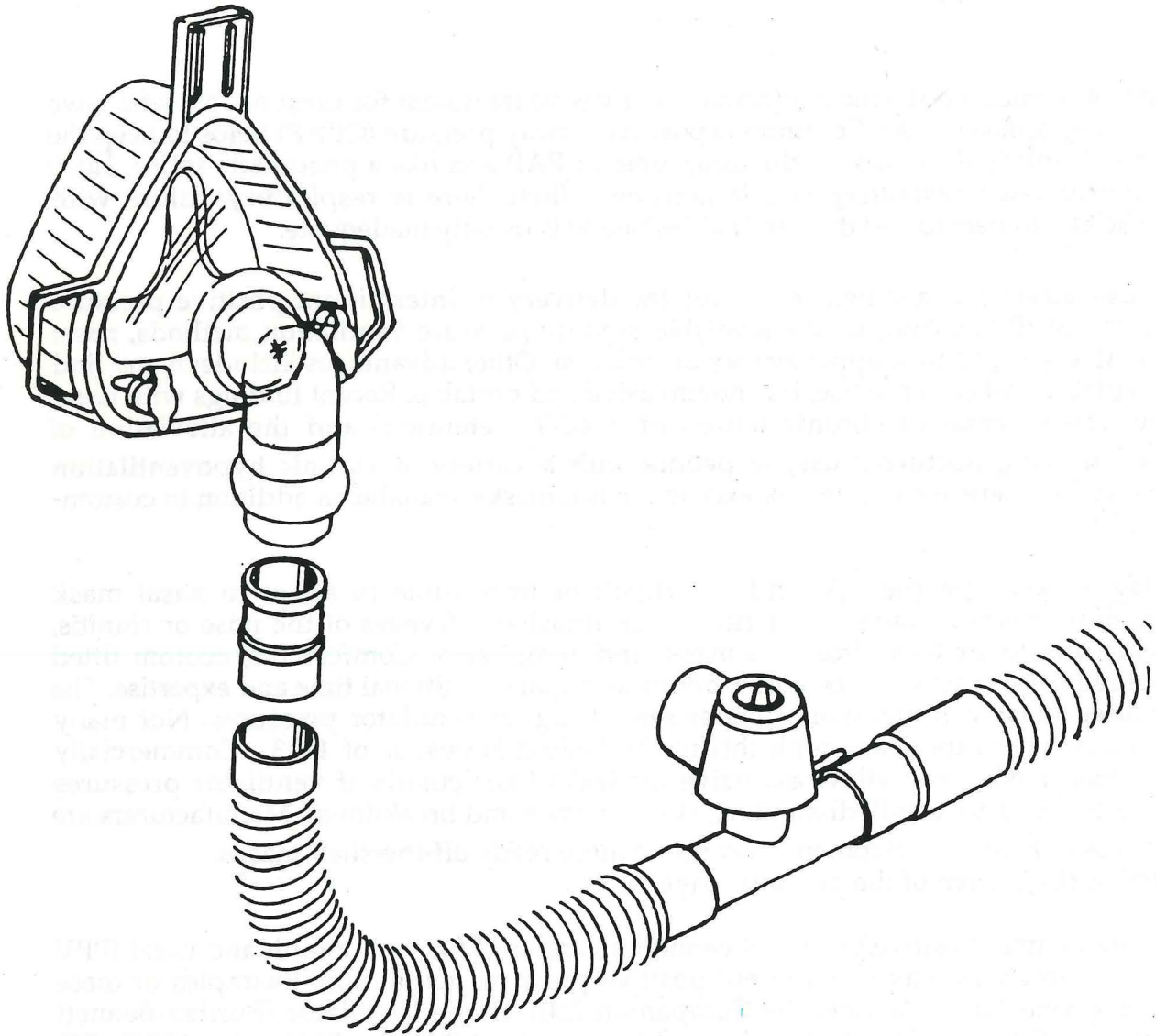
## Nasal Continuous Positive Airway Pressure (Nasal CPAP)

Nasal CPAP is considered the most effective noninvasive treatment for most people who have obstructive sleep apnea (OSA). Continuous positive airway pressure (CPAP) helps to keep the airways and alveoli (the air sacs) in the lungs open. CPAP acts like a pneumatic splint, *but it does not directly assist ventilatory muscle function*. When there is respiratory failure with increased PaCO<sub>2</sub> (hypercapnea) the use of CPAP alone is usually inadequate.

The nose also offers a convenient route for the delivery of intermittent positive pressure ventilation (nasal IPPV). And, unlike available *negative* pressure ventilation methods, nasal CPAP is not likely to produce upper airway obstruction. Other advantages include: many find it more acceptable and easier to use; it is noninvasive and portable. Recent findings with nasal IPPV show the reversal of chronic hypercarbia (CO<sub>2</sub> retention) and the alleviation of symptoms following nocturnal use, in people with a variety of chronic hypoventilation syndromes. Today there are a variety of excellent nasal masks available in addition to custom-molded masks.

Disadvantages: Some people still find it difficult or impossible to adapt to nasal mask ventilation. Side-effects include: skin irritation or abrasions; dryness of the nose or rhinitis; conjunctivitis due to air leaks from the mask; and aerophagia. Comfortable, custom fitted silicone molded nasal masks can be made; but these require additional time and expertise. The custom-molded mask can maintain a better seal at higher ventilator pressures. Not many medical centers have experience with this in the United States, as of 1993. Commercially produced nasal masks may allow excessive air leaks (particularly if ventilator pressures exceeding 25 cm H<sub>2</sub>O are used), discomfort, skin irritation and breakdown. Manufacturers are continuing research and development to improve these ready off-the-shelf masks. (See: "**Note**" at the bottom of the previous page.)

The same small home (positive pressure) ventilators are used for face, mouth and nasal IPPV as are used for tracheostomy intermittent positive pressure ventilation. Examples of these portable home ventilators include: the Companion 2801 Home Ventilator (Puritan-Bennett Corp., Carlsbad, CA); the LP-10 (Aequitron, Minneapolis, MN), the PLV-102 (LIFECARE, Lafayette, CO), and the Bear 33 ventilator (Bear Medical Systems, Inc., Riverside, CA). Additional new, less expensive, simpler and easier to use ventilators are being developed specifically for nasal IPPV, for people who do not need 24 hour mechanical ventilation, such as: the BiPAP S® and BiPAP S/T® (Respironics Inc., Murrysville, PA); the BromptonPAC (PneuPAC Limited, England); and VENTIL+ (SEFAM, France).



**Detail drawing of Respironics Inc. Nasal Mask with Swivel and Circuit**

## Bilevel Ventilation and Nasal BiPAP®

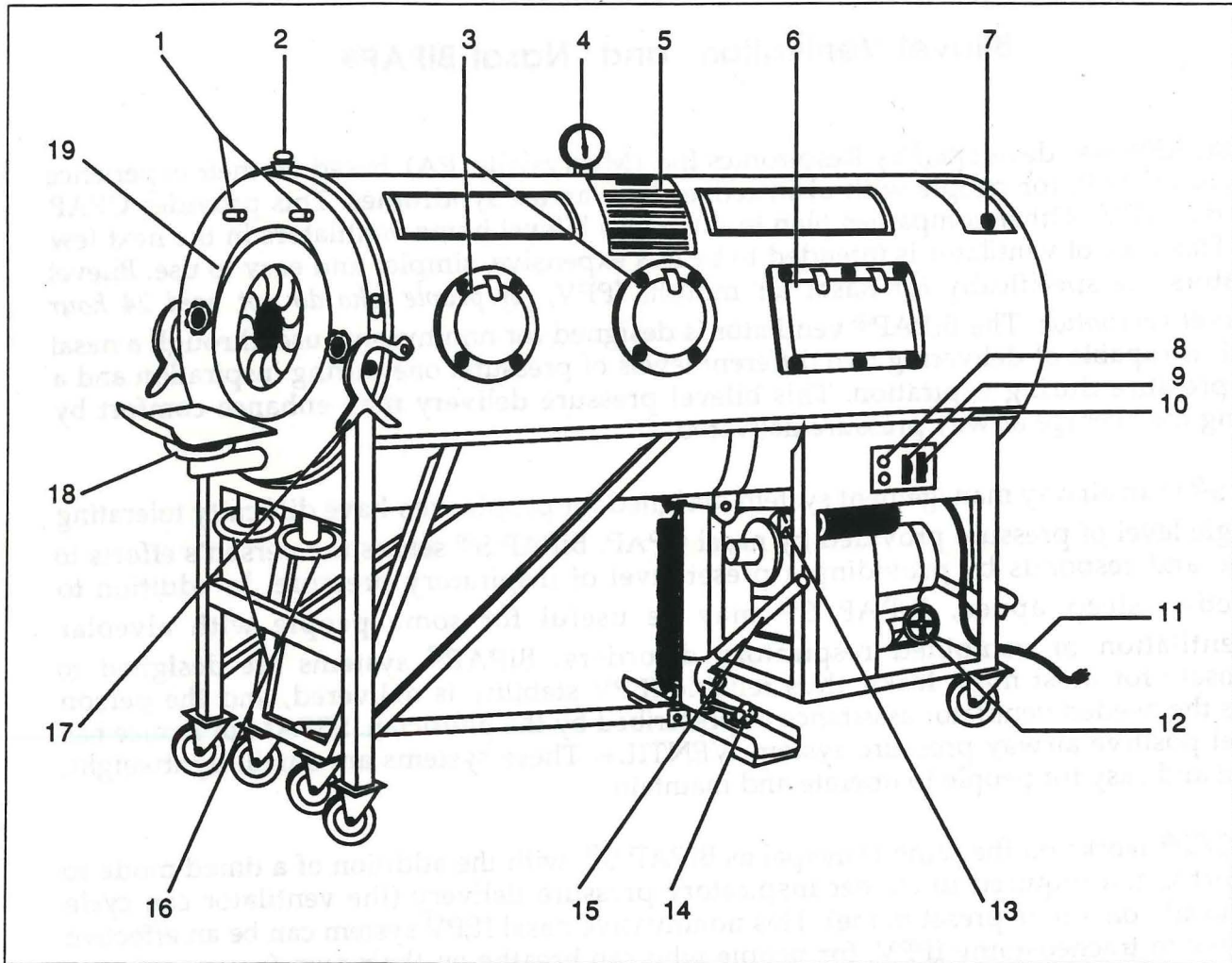
Nasal BiPAP® was developed by Respironics Inc. (Murrysville, PA), based on their experience with nasal CPAP, for people with obstructive sleep apnea syndromes. This provides CPAP plus nasal IPPV. Other companies plan to introduce bilevel home ventilators in the next few years. This type of ventilator is intended to be less expensive, simpler and easy to use. Bilevel ventilators are specifically for nasal (or mouth) IPPV, *for people who do not need 24 hour mechanical ventilation*. The BiPAP® ventilator is designed for noninvasive use, through a nasal mask. It is capable of delivering two different levels of pressure: one during inspiration and a lower pressure during expiration. This bilevel pressure delivery may enhance comfort by lowering the average airway pressure delivered.

BiPAP S® is an airway management system designed for people who have difficulty tolerating the single level of pressure provided by nasal CPAP. BiPAP S® senses the person's efforts to breathe, and responds by providing a preset level of inspiratory pressure. In addition to obstructive sleep apnea, BiPAP S® may be useful for some people with alveolar hypoventilation or combined respiratory disorders. BiPAP® systems are designed to compensate for most mask leaks; thus reliable IPPV stability is delivered, and the person receives the needed ventilator assistance as prescribed by the physician. SEFAM in France has a bilevel positive airway pressure system, VENTIL+. These systems are small, lightweight, portable and easy for people to operate and maintain.

BiPAP S/T® works on the same principal as BiPAP S®, with the addition of a timed mode so that effort is not required to trigger inspiratory pressure delivery (the ventilator can cycle automatically on a time preset mode). This noninvasive nasal IPPV system can be an effective alternative to tracheostomy IPPV, for people who can breathe on their own for many hours each day.

The disadvantages of the currently available bilevel ventilators are: the absence of alarms; the absence of a battery; and uncomfortable dryness in the nose and mouth if airflow is high through the nose when the mouth is opened.

**Description of  
Controls and  
Features**



1. Mirror Support - Use to attach mirror accessory.
2. Intravenous Tube Opening - This is normally plugged but can be used if intravenous application is desired.
3. Access Ports (with Neoprene cuffs)
4. Pressure Manometer
5. Instruction Label
6. Bed-Pan Port
7. Positive Pressure Control (from 0 to 15cm H<sub>2</sub>O)
8. Auxiliary Electric Outlets - These will supply power whenever the power cord is plugged in.
9. Power Switch
10. Light Switch - Operates light inside Iron Lung.
11. Power Cord - Plug in to 120 VAC outlet.



## Tank Ventilator — “Iron Lung”

The tank ventilator or “iron lung” was the first negative pressure ventilator. The original iron lung was designed in 1928 by Drinker and Shaw, and then produced by the J.H. Emerson Company. It has been used for years by people who have severe respiratory muscle weakness. This is the most reliable, precisely controlled and efficient negative-pressure ventilator available. The tank ventilator applies intermittent negative pressure to the entire body below the neck. Ventilation occurs by pumping air out of the iron lung and back into it again, in a preset cycle, which creates a partial vacuum (negative pressure) in the space around the person, causing the chest and lungs to expand (inspiration). Ventilator rate and negative pressure are controlled. The tidal volume of each breath is proportional to the negative pressure generated. It can be used to support people with virtually no ventilatory reserve who require constantly controlled breathing. A tracheostomy is not usually necessary unless required due to upper airway obstruction or excessive bronchial secretions.

Now tank ventilators such as the Porta-Lung, and the British-made Cape Alligator or Rotator, are designed to be quicker and easier to get into and out of them. Recently, a tank ventilator has been designed in which *self-insertion* and release are possible for people with a moderate amount of arm strength. The Porta-lung is a smaller fiberglass version of the “iron lung” or tank ventilator. LIFE CARE, will recondition and service the Emerson Iron Lung.

Disadvantages of the tank ventilator include: [1] They are large in size, cumbersome, heavy, imposing. [2] Once inside a non-self-release tank, the user cannot release themselves and must have assistance from another person to be released. People may dislike this forced dependency. As a result, acceptance of the tank ventilator may be limited. Now a few models are portable, and some have self-release closures. [3] The negative pressure can cause upper airways collapse and thus airflow obstruction, blocking airflow, during sleep for some people. [4] Rarely pooling of blood in the abdomen occurs, which can lower the blood pressure, and then “tank shock” can occur, with collapse due to the low blood pressure.

## Raincoat Ventilator — "Pneumowrap"

The raincoat, "pneumowrap", or Emerson wrap works on the same principle as the iron lung; it encloses most of the body in a plastic wrap envelop. The raincoat/poncho type material is connected to a negative pressure ventilator which pumps air out of the raincoat and back into it again, in a preset cycle, which creates a partial vacuum (negative pressure) in the space around the person, causing the chest and lungs to expand (inspiration). The small portable ventilators used for this and for the chest cuirass include: the Puritan-Bennett Thompson Maxivent, and the LIFECARE NEV-100 and 170C.

The raincoat or "pneumowrap" looks much like some ordinary raincoats or ponchos. It is fastened at the person's neck, wrists, and ankles, and is connected to a ventilator by means of a large diameter air hose. The ventilator self-cycles air out of and into the raincoat at the required set rate and pressure.

Advantages of the raincoat or "pneumowrap" include: [1] It does not require a tracheostomy. [2] It allows the person to lie flat during sleep yet have controlled assisted breathing. [3] It is much more portable than a tank ventilator.

Disadvantages of the raincoat or "pneumowrap" include: [1] It often requires a helper (sometimes two helpers may be needed) to put it on, hook it up to the ventilator, and to take it off. This is cumbersome. People may dislike this forced dependency. [2] The negative pressure can cause upper airways collapse and airflow obstruction during sleep for some people. [3] It is less efficient than a tank ventilator, and may not allow the breathing muscles to rest. [4] It is possible to fail to achieve the needed amount of assisted ventilation. This method will usually not work for an apneic person (who cannot breathe at all without mechanical ventilation). [5] Pooling of blood in the abdomen occasionally occurs, which can lower the blood pressure, and then "tank shock" can occur. [6] It is usually necessary to get out of the "pneumowrap" to use the toilet, and either breathe independently or have another alternative available to assist ventilation at these times.

*Examples:* Pulmo-Wrap® and Nu-Mo® Garment, and Emerson wrap.

### Chest Cuirass — "Chest Shell"

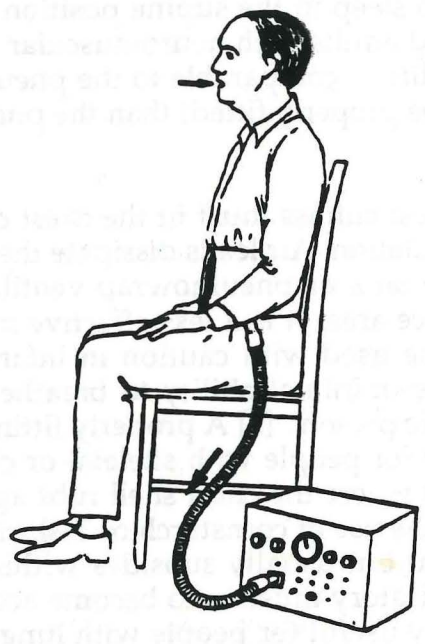
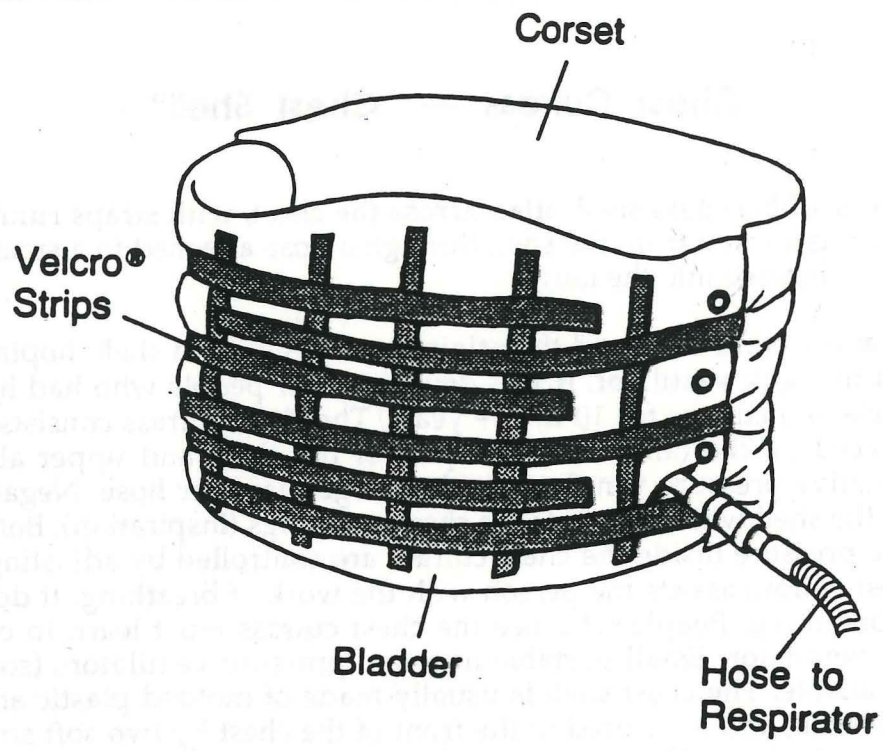
The chest cuirass is a fiber-glass shell fitted across the chest, with straps running around the back. Whenever air is sucked from the shell through a hose attached to a small ventilator, the chest rises and air is inhaled into the lungs.

In 1939 Drinker and Collins designed the original cuirass, a rigid shell, hoping to reduce the disadvantages of the tank ventilator. It was developed for people who had had polio. Many have had good use of a cuirass for 10 to 30+ years. The chest cuirass consists of a rigid shell that is firmly placed on the (anterior) front part of the chest and upper abdomen, and is attached to a negative pressure ventilator with a large diameter hose. Negative pressure is generated inside the shell which expands the chest and lungs (inspiration). Both the ventilator rate and negative pressure inside the chest cuirass are controlled by adjusting the ventilator settings. The chest cuirass assists the person with the work of breathing. It does not perform all the work of breathing. People who use the chest cuirass must learn to coordinate their breaths with the ventilator. Small portable negative pressure ventilators (sometimes called "drivers") are available. The chest shell is usually made of molded plastic and fiberglass. It looks like a turtle shell, and is secured to the front of the chest by two soft stretchable velcro straps. The small portable ventilators used are the same as those used with the pneumowrap.

Advantages of the chest cuirass include: [1] Once it is properly fitted, the chest cuirass is much easier to apply than either the pneumowrap or the tank ventilator. It can be used by people who have to sleep alone. [2] It also allows the user to sleep in the supine position. [3] This mode of ventilation may be ideal for older children and adults with neuromuscular disorders and less rigorous ventilator requirements. [4] Portability is comparable to the pneumowrap. [5] It provides more effective ventilation (when it can be properly fitted) than the pneumobelt, and is probably better than the pneumowrap.

Disadvantages of the chest cuirass include: [1] The chest cuirass must fit the chest closely, to avoid large air leaks, in order to provide adequate ventilation. Air leaks dissipate the negative pressure and limit chest expansion. Compared to the tank or pneumowrap ventilators, the cuirass applies negative pressure over a smaller surface area. It is a less effective method of ventilation than the tank ventilator. And, it should be used with caution in infants, small children and others with minimal ventilatory reserve (minimal ability to breathe on their own). This will usually not work for a completely apneic person. [2] A properly fitting cuirass shell can sometimes be difficult to obtain, particularly for people with skeletal or chest wall deformities. [3] Skin irritation can occur in those areas where the chest shell rubs against the skin. Skin chafing usually occurs if the fit is too loose; the use of cornstarch or T-shirts may be helpful. Chest wall tenderness is a common complaint but usually subsides within several weeks. [4] It may take several days for the user's respiratory muscles to become accustomed to the suction and force of the shell. [5] It is not usually useful for people with lung diseases that require mechanical ventilation, such as COPD. [6] The negative pressure can cause upper airways collapse and thus airflow obstruction during sleep for some people.

Dr. Geoffrey Spencer (London, England) has described how to make custom fitted cuirass shells from a plaster of Paris mold/cast of the torso. This is essential for people with a nonstandard chest shape or scoliosis. The detailed instructions are available from the I.V.U.N. (see listing at the end of the manual). Dr. Spencer discussed this in his article published in the Rehabilitation Gazette (1981) 24:49-50.



### Exsufflation Belt — "Pneumobelt"

The exsufflation belt or the "pneumobelt" works by *augmenting expiration*, the breathing out phase. It consists of a belt which is connected to a self-cycling positive pressure ventilator. The exsufflation belt is applied around the abdomen and lower chest. It intermittently inflates at a preset rate, forcing air out of the lungs and chest cavity. The person using the pneumobelt needs to synchronize breathing with the time cycle of the belt. The exsufflation belt may *assist* the user to generate a *deeper* (bigger) breath than can be obtained without it. The pneumobelt is an adjustable cloth corset with an inflatable bag, which fits around the person's abdomen. As the bag inflates, the abdominal contents are compressed, the abdomen rises, and exhalation occurs. As the bag deflates, the diaphragm lowers, and inspiration occurs passively. Because this method utilizes gravitational forces, it is effective only in the sitting and standing positions. An acclimatization period exists with each person. Sometimes there is immediate relief, but it often takes several days to adjust and learn.

The advantages of the pneumobelt include: [1] Its small size, portability, light weight, and inconspicuous appearance. [2] It can easily be used when sitting up during the day. [3] It does not interfere with the face or arms. [4] It easily allows speaking and eating. [5] It may be concealed under clothing. [6] The ventilator can be mounted on a wheelchair along with a battery. [7] For some people this is more comfortable and effective than negative pressure ventilation, such as the chest cuirass.

Disadvantages of the pneumobelt include: [1] Some people experience great difficulty synchronizing their breathing with the time cycle of the belt. [2] Others are unable to use the belt because they have abdominal muscles that are too tensed or toned. [3] The pneumobelt's greatest disadvantage is that the user must remain at a 45° to 90° angle (standing, seated or reclined) since it relies on gravity to pull the diaphragm downward during inhalation. This limits its nocturnal use, unless one sleeps sitting up. [4] It is often considered to be a less effective method of ventilation than the tank ventilator or the cuirass. This method will usually not work for someone who is completely apneic (unable to breathe independently at all). [5] Nausea may occur if used after meals; and, some people experience low back pain.

Two ventilators that can be used to operate the pneumobelt include: the Puritan-Bennett Companion® 2500 or the LIFECARE PLV-100. Because of one-way valving to eliminate the possibility of rebreathing, most of the other portable volume controlled ventilators are not used for the pneumobelt.

## Rocking Bed

The rocking bed works by tilting the person's body through an arc of about 40° at rates ranging from 13 to 19 times per minute. The abdominal contents and diaphragm slide back and forth as the body tilts, assisting ventilation.

Advantages of the rocking bed include: [1] It is noninvasive and can be used during the day for naps, and during sleep at night. [2] For people with normal lungs, and a neuromuscular cause of respiratory failure (*such as* diaphragmatic paralysis) and less rigorous ventilator requirements, this method can be useful. Such people are often able to breathe independently when sitting or standing upright, but are unable to breathe when they lie down. In these cases a rocking bed may allow safe and comfortable sleep.

Disadvantages of the rocking bed: [1] The rocking bed may function poorly for excessively obese, thin, or scoliotic individuals. It should also be used with caution in individuals with minimal pulmonary reserve (minimal ability to breathe on their own). [2] It usually cannot provide as highly effective ventilation as the other negative pressure techniques already discussed. [3] It is not a portable method.

LIFECARE, reconditions and services rocking beds.

## Tracheostomy

*Indications for tracheostomy intermittent positive pressure ventilation (TIPPV):* Tracheostomy is normally used by people who need nearly 24-hour per day mechanical ventilation. Some people use TIPPV for only 8–12 hours/day. Other indications for a permanent tracheostomy in individuals with chronic respiratory failure (hypoventilation) include: [1] poor control of symptoms or persistent hypercarbia (elevated  $\text{CO}_2$ ) with noninvasive ventilatory assistance; [2] inability to clear bronchial secretions; [3] problems with aspiration; [4] deterioration of neuromuscular disease so that spontaneous ventilation becomes intolerably brief; and [5] failure of nasal CPAP and nasal ventilation in those with severe sleep apnea syndrome.

Positive pressure ventilator assistance is usually administered either nocturnally or continuously, using one of several commercially available portable volume ventilators. The rate, number of breaths per minute, can be either controlled (set), or triggered by the person (assisted). If the "assist/control" mode is used, it is generally best to set the rate to that which is usually required in order to avoid the work of breathing to initiate each breath. *The advantages of tracheostomy IPPV include:* [1] It is very effective. [2] It can be provided by relatively simple equipment which is small and convenient. [3] Ventilators can be attached to or incorporated in wheelchairs, or other mobile carrying devices (e.g.: carts, pedestals, etc.). [4] This is the method most familiar to health care professionals in the United States who have been trained in hospital intensive respiratory care.

*Examples of portable ventilators:* the Companion<sup>®</sup> 2801 Home Ventilator (Puritan-Bennett Corp., Carlsbad, CA); the LP-10 (Aequitron, Minneapolis, MN); the PLV-102 (LIFECARE, Lafayette, CO); the Bear 33 ventilator (Bear Medical Systems, Inc., Riverside, CA); BiPAP<sup>®</sup> S and BiPAP<sup>®</sup> S/T (Respironics Inc., Murrysville, PA); and the BromptonPAC (PneuPAC Ltd., England).

With creation of an air leak around the tracheostomy tube cuff (partially or completely deflating the cuff), or by using an uncuffed or fenestrated tracheostomy tube, when this is possible, speech can be satisfactory. Speech is intermittent during the inspiratory phase of the ventilator unless a speaking valve is used, such as the Passy-Muir valve. When a cuffless tracheostomy tube is used, or when the cuff is kept deflated, it is important to check the adequacy of night-time ventilation. Hypoventilation may occur at night unless the cuff is inflated at night or pressure controlled ventilation is used. Pressure controlled ventilation adjusts for variable air leak around the tracheostomy tube. Dr. I.S. Gilgoff has described the importance of this in CHEST (1992) 101:1500-1506.

*Disadvantages of tracheostomy:* [1] Placement of a permanent tracheostomy tube complicates the care of people with chronic respiratory failure because it necessitates suctioning and stoma care (these are sometimes called *nursing* tasks). However, properly selected and prepared, many people with a tracheostomy manage quite successfully in the home setting. It is also helpful to have a supportive family and sufficient resources. [2] During the first year the tracheostomy stoma matures, and sometimes needs ENT physician care periodically to treat granulations and make adjustments. [3] The tracheostomy may be a route for infection. [4] It can erode surrounding anatomical structures with minor or massive bleeding. [5] It impairs glossopharyngeal augmented breathing techniques, and effective normal cough. [6] Some people are reluctant to undergo tracheostomy because it is invasive, and they feel that it increases their disability and dependence; makes them look less like a normal person; and might prevent them from wearing certain articles of clothing such as a collar or tie. [7] Some people have difficulty with speech or swallowing as a result of tracheostomy.

## Phrenic Nerve Pacing

Phrenic nerve pacing (also called diaphragm pacing, or electrophrenic respiration) generates breathing using the person's own diaphragm as the respiratory pump. The technique involves surgical implantation of electrodes around the intrathoracic phrenic nerves. The electrodes are connected to small receivers implanted subcutaneously (beneath the skin). The phrenic nerves are electrically stimulated transcutaneously from an external power source. Power is transmitted in a manner similar to radio transmission. Pacer rate and electrical current settings can be controlled. This determines the respiratory frequency and size of each breath. Tidal volume is proportional to the electrical current used to stimulate each breath. Effective ventilation can be generated using simultaneous bilateral diaphragm pacing in infants, children, and adults if the phrenic nerves and diaphragms are functional. This technique has had variable success in some people with central hypoventilation syndrome, COPD, and some people with high-level spinal cord injury.

The diaphragm pacer is small, light, and easily portable. It is battery operated. However, the surgical technique is tricky and use of the pacer once implanted requires a fair amount of experience. Diaphragm pacing is currently being performed at only a few centers. Available phrenic nerve pacing systems include: Avery Laboratories, Inc. (Farmingdale, N.Y.); Dobelle Institute (Glen Cove, N.Y.); and Atrostim from Finland (distributed in the United States by Medlink Technical Corp., Los Angeles, CA).

*Disadvantages include:* [1] The effectiveness of diaphragm pacing may be compromised by intermittent upper airway obstruction; thus permanent tracheostomy or nasal CPAP is required for most people. [2] Since phrenic nerve stimulation causes diaphragmatic contraction, diaphragm pacing is contraindicated in people with primary phrenic nerve damage or primary diaphragm myopathy. [3] Operative risks, including infection and trauma to the phrenic nerves which are easily damaged. [4] The surgery plus in-hospital training of four to six weeks, are very expensive. [5] Sudden operational failure may occur, and there is no built-in alarm system. [6] Phrenic nerve pacing makes using the glossopharyngeal breathing technique difficult. [7] Irreparable phrenic nerve and diaphragm muscle injury may occur if continued pacing causes neuromuscular fatigue.



## Bronchial Clearance & Cough Augmentation

Bronchial clearance of secretions is specially important when effective cough is impaired, when bronchitis results in increased secretions, *or* when there is aspiration. Training from a respiratory or physical therapist may be very helpful. Sometimes medications help to improve bronchial clearance, such as bronchodilator medication. Chest physiotherapy with percussion and postural drainage may be useful in selected situations. Electric percussors are an alternative to manual percussion techniques. Sortor and McKenzie\* have produced a helpful training video in 1986, *see* below. Mechanical exsufflation devices were manufactured in the past (*e.g.*: the Cof-flator cough machine, OEM Co.; *it is no longer produced.*), and can be very helpful when available. Dr. John Bach emphasizes their key importance; they can provide enough assistance so that intubation or tracheostomy may not be necessary\*\*. However few physicians have experience using mechanical exsufflation devices, which were more available in the 1950s. The J.H. Emerson Co.(Cambridge, MA) has a new In-Exsufflator cough machine available in 1993. Other augmentation methods include: positive-expiratory-pressure (PEP) mask therapy, to help mobilize secretions, instead of chest physiotherapy or in addition to it (*see* the reference below, by M. J. Mahlmeister, *et al.*); and mechanical oscillation devices, such as the Hayek oscillator (Flexco Medical Instruments AG, Zurich, Switzerland) and the Jamil Pro (CIME Electronique médicale, Marseille, France).

## Glossopharyngeal Breathing Technique (GPB)

Glossopharyngeal breathing technique was developed by serendipity in the early 1950s by a person with poliomyelitis highly dependent on ventilation from an iron lung; it allowed unexpected periods of time off the ventilator several hours each day. This method was subsequently developed and taught effectively to many other polio survivors and a few people with other neuromuscular conditions. It has allowed people to increase tidal volume by two to three times, by gulping and forcing or "stroking" additional boluses of air into the lungs (sometimes called "frog breathing"). This has been used to increase the ability for independent breathing, to improve cough, to decrease the tendency toward atelectasis, and to increase someone's margin of safety in the event of power or mechanical failure of the ventilator. GPB may increase thoracic and chest wall function. Thus, *for selected individuals*, learning GPB, has extended their functional capabilities without respiratory assistance (mechanical ventilation). The professional staff at Rancho Los Amigos Hospital have had considerable experience teaching and using this technique (*see* the 1979 publication by C. Dail, *et al.*).

\*Susan Sortor and M. McKenzie have produced a video: "*Toward Independence: Assisted Cough*" (1986). BioScience Communications of Dallas, Texas. Dallas Rehabilitation Institute, 9713 Harry Hines Boulevard, Dallas, Texas 75220-5441.

\*\*Mechanical exsufflation devices are discussed further in many publications, such as: John R. Bach, *et al.* in *CHEST* (1993) 103:174-182; John R. Bach and Augusta S. Alba, in *CHEST* (1990) 97:52-57 (p.56-57); and, *see also* the older references: Barach *et al.*, *and* Bickerman *et al.*, - noted by Bach and Alba (1990).

## Oxygen

Oxygen is available for use in the home, *or* portable oxygen can be used outside of the home, only if it is medically indicated. It may be delivered with devices such as: nasal prongs, trans-tracheal catheter, connected to tracheostomy, oxygen mask, or ventilator. Available home oxygen equipment includes: electric oxygen concentrators, compressed tank oxygen, and liquid oxygen systems (which are easily portable and used for ambulation outside the home). Oxygen may be prescribed by a physician if it is *medically necessary*, usually based on arterial blood gas (ABG) measurements made when a person is medically stable. The usual medical indication is hypoxia, an arterial  $\text{PaO}_2 \leq 55$  mm Hg, *or* an oxygen saturation of  $\leq 88\%$ . An oximeter can measure oxygen saturation ( $\text{SaO}_2$ ) noninvasively, but an oximeter does not measure pH or  $\text{PaCO}_2$  — *which can be very important*. Oxygen is usually administered, when necessary, continuously 24-hour per day. It may be given by nasal prongs, by mask, by trans-tracheal catheter, by an attachment to the tracheostomy, or through a mechanical ventilator system. The amount of oxygen needs to be carefully regulated at a specified flow rate (liters per minute) *or* concentration (per cent). Too little oxygen will not provide the oxygen needed by body tissues; too much oxygen can sometimes depress the breathing control center and lead to respiratory failure and collapse. (See: the 1992 article by Walter J. O'Donohue, Jr. — in the reference section at the end of the manual.) Oxygen is not useful, and should not be used, for shortness of breath or respiratory symptoms *when the arterial oxygen level is satisfactory*.

→ **The Lung Patient's Guide to the Use of Home Oxygen** and other patient information materials may be obtained from your local office of the American Lung Association (ALA) in California; or, contact the ALA of California, 424 Pendleton Way, Oakland, CA 94621-2189. (510) 638-5864.

## Physical Medicine & Rehabilitation

Physical medicine and rehabilitation can provide important evaluation and treatment for people with respiratory diseases of many types. People with neuromuscular disease or musculoskeletal disease may particularly benefit from evaluation and follow-up care, as needed, from a physician in physical medicine and/or other rehabilitation professionals such as: physical therapist, occupational therapist, respiratory care practitioner, social worker, speech or communication therapist, ... A pulmonary medicine physician should also participate in the evaluation and management. Pulmonary rehabilitation aims to restore people to an independent, productive and satisfying life.

## Tracheostomy & Ventilator Speaking Valves

Passy-Muir tracheostomy and ventilator speaking valves: A one-way valve attached to a cuffless tracheostomy to augment airflow on expiration through the vocal cords and upper airway, to enable speech. It redirects airflow during exhalation, through the upper airway, for speech and also clears secretions. The Passy-Muir valve must be prescribed by a physician, and can be used with a fenestrated tracheostomy with the inner cannula removed, with a cuffless tracheostomy, and sometimes with a completely deflated cuff tracheostomy. **Caution if there is a cuff on the tracheostomy: dangerous complications occur if the cuff is inflated with the valve.** Air must be able to move through or around the tracheostomy during exhalation, since the valve blocks airflow out of the tracheostomy orifice or the ventilator circuit. Selected people using a *cuffless* tracheostomy can use this valve in their ventilator circuit to augment the ability to talk while on the ventilator. The Passy-Muir Tracheostomy Speaking Valve is the only valve that can be used in-line with the ventilator. If stomal leaks are a problem, stomal padding may be useful. The Lyofoam stomal pad provides a positive seal to the stoma inhibiting air escape, and may be more effective than gauze pads. It is made by ACME Medical (Fairfield, CT - telephone: 800-TEL-ACME). Benefits include: spontaneous speech, a louder voice with more control for sentence structuring, hands free speech, better stomal hygiene to user and environment (it eliminates the need for finger occlusion), and better secretion management. A respiratory care practitioner familiar with this valve needs to assess the safety of the system and adjust the ventilator settings to compensate for any increased leak, with physician involvement. Consultation by a speech and communication specialist, who is experienced with helping people who use a tracheostomy or ventilator, is recommended. Portex, Inc. (Keene, NH) and National Catheter Co. (Argyle, NY) manufacture cuffed talking tracheostomy tubes that provide an independent flow of air through a small tube on the outer wall of the tracheostomy tube. The air flow at 4 to 8 liters per minute exits above (proximal to) the cuff, providing air flow through the vocal cords for speech, when the finger control port is occluded.

Alternatives to augment speech, with only a tracheostomy include: the Olympic Trach-Talk™ and Trach-Button™; the Kistner trach button; and the Montgomery silicone tracheal cannula (Boston Medical Products, Waltham, MA) also comes with a one-way speaking valve. These should not be used in-line with the ventilator.

In some cases, particularly when there are neurologic problems limiting speech, an augmentive or alternative communication system may be needed. There are many alternatives available. Evaluation by a speech-language pathologist familiar with these systems is recommended. The systems available include simple inexpensive devices, as well as very sophisticated portable communication devices with high quality synthesized speech, such as: System 2000™ (Words+, Inc., Lancaster, CA.); the Lightwriter (Toby Churchill Ltd., Cambridge, England); and the Liberator™ (Prentke Romich Company, Wooster, Ohio).

**Pulmonary Function Testing; Prevention; Other Diseases; Advance Directives**

**Pulmonary Function Testing (PFT):** PFT provides baseline assessment and follow-up monitoring. Often simple tests which measure ventilation, arterial blood gases and oxygen saturation, can provide very helpful information. For example: maximal inspiratory and expiratory pressures and vital capacity can be very useful in monitoring neuromuscular and musculoskeletal diseases. PFT information indicates whether there is respiratory impairment, how severe, how quickly it is progressing, whether there is much remaining reserve, whether a critical action point is present. Testing is usually done sitting or standing, but should also be done supine if symptoms occur mostly (or particularly) when lying down. PFT is useful for both initial evaluation *and* follow-up. Selected tests are important *periodically* for people who use oxygen *or* use a ventilator at home, – to be sure the settings are correct for rest, activity, and during sleep.

**Prevention:** Keep as healthy as possible to prevent respiratory complications or delay their onset. Maintain a healthy diet, regular rest and sleep, and appropriate exercise and activity. Avoid cigarette smoke, excess weight, over-doing to the point of fatigue. Obtain immunizations, including Pneumovax and yearly Influenza. Avoid close contact with anyone who has a viral infection, such as a cold or “flu”. Treat any respiratory problem promptly, such as a cold with chest congestion, fever, and yellow or green phlegm. Check any problem with swallowing, or aspiration, promptly before major complications occur.

**Other Diseases:** Sometimes there are other medical problems that contribute to impair breathing, and need to be considered. Many of these can be treated and improved, but if not treated, could be enough to cause avoidable respiratory complications or critical respiratory failure. These include: anemia, hypothyroidism, obesity, electrolyte imbalance, kidney failure, heart failure, swallowing problems with aspiration, hypoxemia, other lung disease, medication side-effects, and infection. Regular careful complete medical evaluation and care is important, in addition to appointments with specialists. Be sure to have regular appointments.

**Advance Directives:** *Emergency Planning:* You and your family, with advice from your physician, should have a plan of action for various medical emergencies that might occur. You should have a list of emergency phone numbers, and know any extra medications to use when your regular ones are not enough. Ask your physician for advice. It may be helpful to consult with a medical social worker in addition. *Advance directives:* such as the Durable Power of Attorney for Health Care (DPAHC) should be reviewed with your family *and* physician, so that they know your preferences and can assist you. You should periodically complete and update your DPAHC. For people who do not like to complete forms, the minimum would be to discuss the issues clearly with your family and your physician. It is very helpful to write down your preferences. The *Patient Self-Determination Act* is a Federal Law which supports a person’s right to participate in and direct decision making regarding their health care. Further information is available at most hospitals. Each state has laws related to advance directives, and often special forms to use. Copies of “Medical Directive” information may be obtained from The Harvard Medical School Health Publications Group, P.O. Box 380, Boston, MA 02117. The American Association of Retired Persons has many helpful materials (1909 K Street NW, Washington DC 20049) on advance directives, long-term care, caregivers, etc.. Use advance directives to specify the care you want, as well as care you may not want, in different situations. You should also indicate a substitute (proxy) decision maker who could represent your preferences for you, in case you cannot do so yourself.

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## Glossary

- Apnea:** Complete inability to breathe without assistance; cessation of breathing.
- Apnea monitor:** A device used to monitor breathing and to provide an alarm in the event that breathing stops. Several types are available.
- Aspiration:** Breathing into the lungs food, liquid, saliva, stomach contents or other material.
- Assist setting:** When this setting mode is used, the ventilator triggers whenever the person initiates a breath. The ventilator sensitivity is adjusted to sense a minimal effort. The pressure or volume of air delivered is set. The ventilator *assists* each patient-initiated breath. A back-up rate is also set.
- Arterial blood:** The blood which carries oxygen from the heart to the tissues through the systemic arteries of the body.
- Arterial blood gas (ABG):** A test that measures the oxygen, carbon dioxide and pH levels in the arterial blood. The sample is obtained with a needle and syringe.
- Atrophy:** Deterioration or loss of tissue; for example, muscle tissue atrophy.
- Bulbar:** Pertaining to, or involving, the part of the brain known as the medulla oblongata, which is at the top of the spinal column. Bulbar involvement may affect respiration, speech, swallowing and related functions.
- Controlled ventilation:** The ventilator equipment cycles at a set, fixed, rate of breaths per minute. The pressure or volume of air delivered is also set. No effort is needed (nor sensed) to initiate each cycle of the ventilator.
- Cuirass:** A rigid molded external device which encompasses the anterior and lateral aspects of the chest and upper abdomen. It is powered by mechanical ventilation equipment with a motor that creates negative pressure outside the chest wall. *Also called:* a chest shell, a chest respirator.
- CPAP:** Continuous positive airway pressure.
- Cyanosis:** A bluish discoloration of the skin caused by a low oxygen level in the blood.
- Diaphragm:** The most important muscle for breathing. It is located between the chest cavity and the abdominal cavity.
- D.M.E.** Durable medical equipment company; distributor for homecare equipment.
- DPAHC:** Durable power of attorney for health care. A legal document that allows you to record your preferences for treatment or avoiding certain types of care, and it allows you to designate someone to represent you if you are ever unable to competently express your wishes. This is available in most parts of the USA.
- Dysphagia:** Difficulty in swallowing.
- Dyspnea:** Difficult *or* labored breathing.
- Edema:** The abnormal accumulation of fluid in tissues, such as in the ankles or feet.
- Electromyography (EMG):** The recording and study of the intrinsic electrical properties of skeletal muscles and the associated nerves.
- Endotracheal tube:** A plastic tube inserted into the windpipe (trachea) via the nose or mouth. It can be used for suctioning *and* to connect to a ventilator.
- Frog breathing:** Often used as a synonym for glossopharyngeal breathing (GPB) *and* gulping breathing augmentation maneuvers.
- Glossopharyngeal breathing (GPB):** A breathing augmentation method which uses a series of mechanical actions of the lips, tongue (glosso), throat (pharyngeal), and laryngeal structures to trap, gulp and force air into the lungs. Also called "frog breathing."
- GPB:** *See* glossopharyngeal breathing. *Also called:* "frog breathing."
- Hypercapnea or Hypercarbia:** Elevation of the arterial blood carbon dioxide content due to under-breathing, inadequate ventilation.

- Hyperventilation:** Over-breathing, resulting in lower  $\text{CO}_2$  in the arterial blood.
- Hypoventilation:** Under-breathing, resulting in higher  $\text{CO}_2$  in the blood,  $\text{CO}_2$  retention.
- Hypoxia:** A low arterial blood oxygen content.
- IPPV:** Intermittent positive pressure ventilation.
- Intermittent abdominal compression ("pneumobelt"):** A method of artificial breathing based on mechanically forced exhalation. Ventilation is controlled by an adjustable corset with an inflatable bag ("pneumobelt") which fits around the person's abdomen.
- Intubation:** Insertion of a tube into any body orifice, often for respiratory support, inserted into the nose, mouth, or trachea (windpipe).
- Iron lung:** The original colloquial term for a negative pressure tank respirator.
- Life-support IPPV:** Usually indicating that the person needs to use the ventilator continuously in order to live; generally not able to be off the ventilator at all, or for only an hour or less per day.
- Mouth IPPV:** Mouth intermittent positive pressure ventilation. A method of delivering air at a controlled amount of pressure, through a mouthpiece held securely between the lips. The rate, number of breaths per minute, can be either controlled (set) or triggered by the person (assisted).
- Nasal IPPV:** Nasal intermittent positive pressure ventilation.
- Negative pressure ventilation:** Providing inflation of the lungs by a method that creates intermittent negative pressure around the outside of the body or the chest.
- Oximeter:** A photoelectric device that can be attached to the finger, or other area, by which oxygen saturation of the capillary blood can be measured non-invasively.
- Orthotic:** A specially designed device or appliance, such as to attach a ventilator to a person's mouth or nose, or to provide a brace or support to weakened muscles or joints.
- Palliative:** Care or treatment to provide comfort or relieve symptoms, while not curing.
- Passy-Muir speaking valve:** A one-way valve attached to the tracheostomy to augment airflow on expiration through the vocal cords and upper airway, to enable speech. Used sometimes for selected TIPPV people.
- PEP:** Positive-expiratory-pressure.
- PEEP:** Positive *end*-expiratory pressure. A mode *not* usually used for home care.
- Pneumobelt:** A method of artificial breathing based on mechanically forced exhalation. Ventilation is controlled by an adjustable corset with an inflatable bag ("pneumobelt") which fits around the person's abdomen. *Also called:* intermittent abdominal compression.
- Positive pressure ventilators:** Ventilators which *deliver air*, under controlled pressure or volume, *into* the lungs. A number of interface connections from ventilator to patient can be used, such as a mouthpiece, mask, or tracheostomy.
- Postural drainage:** Therapeutic drainage of secretions from the airways of the lungs, through positioning and rhythmic beating or vibration with the hands or a mechanical device, over the affected lung areas (where secretions pile up).
- Pressure controlled ventilation:** The ventilator provides positive pressure airflow until a set peak inspiratory pressure (PIP) occurs. Some portable volume ventilators can be adjusted to achieve pressure controlled ventilation.
- Refusing care:** A competent adult person, who understands the pros and cons, and is *not* making a hasty decision, or one influenced by depression, can refuse any treatment that is not desired. Health care professionals must respect a person's wishes if they are persistent and informed.

- Respirator:** A device which causes a flow of air in and out of the lungs substituting for or augmenting normal ventilation. A term synonymous with "ventilator," and somewhat less commonly used today.
- Scoliosis:** A sideways curvature of the spine.
- Tank respirator:** A controlled negative pressure chamber in which a person lies with only his/her head and neck outside the chamber. The exchange of air in the lungs occurs by the creation of negative pressure outside the chest wall and upper abdomen. *Also called:* an "iron lung".
- Tidal volume:** The volume of air that is inhaled or exhaled with each breath during breathing.
- TIPPV:** Tracheostomy intermittent positive pressure ventilation. Positive airway pressure ventilation is delivered via tracheostomy, using an external mechanical ventilator such as a pressure or volume cycled machine.
- Tracheostomy:** An incision into the trachea (windpipe), and the insertion of a tube to facilitate breathing and suctioning of secretions.
- Ventilation:** The act of moving air into and out of the lungs.
- Ventilation, mechanical:** Breathing with the aid of a mechanical ventilator (utilizing either positive or negative pressure) to enable movement of air into and out of the lungs.
- Ventilator:** Any device which causes a flow of air into and out of the lungs, substituting for, or augmenting, normal ventilation. Also called a "respirator". This may provide *ventilatory assistance* when the person can breathe independently for significant periods without the ventilator, or it may be for *life-support* when a person would likely die if the ventilator were not available.
- Vital Capacity:** The maximal volume of air (gas) that can be expelled from the lungs after breathing in as deeply as possible. VC = vital capacity.
- Withdrawing care:** A treatment that is not effective can be stopped. Also, a person can request to stop a treatment that is not desired, even if the consequence might be that the medical condition would then lead to death [such as when ventilator care is withdrawn]. The person can request other treatment, or medication to avoid discomfort. Such a request or decision needs to be very carefully reviewed to be sure that all necessary information is available and that it is not hasty nor manipulated.

## Bibliography

### Books, Pamphlets & Videos — for Public and Patient information:

- American Lung Association of California and the California Thoracic Society: The Lung Patient's Guide to the Use of Home Oxygen , Safe Flying for Patients with Lung Disease, and other patient information materials may be obtained from your local office of the American Lung Association (ALA) in California; *or* contact the ALA of California, 424 Pendleton Way, Oakland, California 94621-2189 (510) 638-5864.
- Blitzer, Bud (Ed.): Directory of Sources for Ventilation Face Masks. (1991) Available from IVUN for \$2.50 post-paid. A 16-page illustrated directory. Send request with your check to: International Ventilator Users Network, 5100 Oakland Avenue, #206, Saint Louis, Missouri 63110.
- Chenevert, Basil J.: Taking Hopelessness Out of Helplessness. (1989) J.R.Printing, MetroStaff Home Health Care, Detroit, Michigan. Basil Chenevert, P.O.Box 5031, Southfield, Michigan 48086-5031.
- Dail, C., Rodgers, M., Guess, V., Adkins, H.V.: Glossopharyngeal Breathing. (1979), The Professional Staff Association of the Rancho Los Amigos Hospital, 7601 East Imperial Highway; Downey California 90242; 57 pages.
- Davis, C., Kent, B., Oeser, D., Oppenheimer, E.A., and Baldwin-Myers, A.: How to Hire Home Caregivers. (1992) 20 page manual available from: Adrienne Baldwin-Myers, RNC, Home Ventilator Program, Regional Kaiser Foundation Hospital Administration – 7th floor, 393 East Walnut Street, Pasadena, CA 91188.
- Gazette International Networking Institute (G.I.N.I.): "Personal Assistance Services" (PAS). Rehabilitation Gazette (Jan. 1993) 33 (1): 1-14. Request a copy from I.V.U.N., Saint Louis.
- Hamilton, Lou: Why Didn't Somebody Tell Me About These Things? (1984) Inter-Collegiate Press, Shawnee Mission, Kansas. Lou Hamilton – 217 N. Jeffreys Street, Pleasant Hill, MO 64080. [Out of print.]
- Jones, Monica Loose: Home Care for the Chronically Ill or Disabled Child. A Manual & Sourcebook for Parents and Professionals. (1985) Harper & Row Publishers, New York.
- Preston, W., et al.: Managing Breathing Problems. Managing Amyotrophic Lateral Sclerosis Manual III. (1986) The ALS Association. *MALS Manuals* may be obtained from The ALS Association, 21021 Ventura Blvd., suite 321, Woodland Hills, Calif. 91364
- Schock, Nancy C. and Agatha P. Colbert: Ventilators & Muscular Dystrophy. (1987) Available from I.V.U.N. for \$6.75 post-paid. A 36-page illustrated directory. Send request with your check to: International Ventilator Users Network, 5100 Oakland Avenue, #206, Saint Louis, Missouri 63110.
- Simon, Roberta: "Ventilator Considerations: Lease vs. Purchase." I.V.U.N. NEWS (1991) 5(2):1-2. International Ventilator Users Network (I.V.U.N. –*address as above*).



Sortor, Susan and M.McKenzie: (video) "Toward Independence: Assisted Cough". (1986) BioScience Communications of Dallas, Texas. BioScience Communications of Dallas, Texas. Dallas Rehabilitation Institute, 9713 Harry Hines Boulevard, Dallas, Texas 75220-5441.

Tsieprati, Ismail & Cheryl: • It's Your Choice (1992): and • Caring for the Caregiver (1993). Educational videotapes produced by Valona Productions, 14621 Titus Street – suite 108, Van Nuys, CA 91402. These videos can be obtained for \$20 each from Valona Productions.

**Note:** Often equipment companies, as well as some hospitals and medical centers, have manuals, patient/family education manuals, and related materials available on request.

### Selected Scientific Articles and Books:

American Medical Association: Physicians and Home Care. Guidelines for the Medical Management of the Home Care Patient. (1992) Department of Geriatric Health, A.M.A., Chicago, IL. 23 pages.

Bach, J.R., et al.: Intermittent Positive Pressure Ventilation via the Mouth as an Alternative to Tracheostomy for 257 Ventilator Users. CHEST (1993) 103:174-182.

Bach, J.R. and Beltrame, F.: Alternative Approaches to Home Mechanical Ventilation. *In: Intensive Homcare*, M.M.Rothkopf and J. Askanazi (*Eds.*), Williams & Wilkins, Baltimore (1992). Chapter 12, pp: 173-197.

Bach, John R.: Alternative Methods of Ventilatory Support for the Patient with Ventilatory Failure due to Spinal Cord Injury. J Am Paraplegia Soc (1991) 14:158-174.

Bach, J.R. and Alba, A.S.: Management Alternatives for Post-Polio Respiratory Insufficiency. Assisted ventilation by nasal or oral-nasal interface. Am.J.Phys.Med.& Rehab. (1989) 68:264-271.

Bach, J.R. and Alba, A.S.: Management of Chronic Alveolar Hypoventilation by Nasal Ventilation. CHEST (1990) 97:52-57.

Bach, J.R. and Alba, A.S.: Tracheostomy Ventilation. A study of efficacy with deflated cuffs and cuffless tubes. CHEST (1990) 97:679-683.

Baldwin-Myers, A.S., Geiger-Bronsky, M., Chacona, A., Ewing, L., Huiskes, B., and Shiroma, J.: Standards of care for the ventilator-assisted individual: A comprehensive management plan. (1992) *Pending publication.*

Brochard, L., et al.: Reversal of Acute Exacerbations of Chronic Obstructive Lung Disease by Inspiratory Assistance with a Face Mask. NEJM (1990) 323:1523-1530.

Burton, G.G.: Respiratory Care. A Guide to Clinical Practice. (1991) J.B.Lippincott Co., Philadelphia.

Callahan D.: Families as caregivers: the limits of morality. Arch Phys Med Rehab, (1988) 69:323-328.

- Carroll, N. and Branthwaite, M.A.: Intermittent positive pressure ventilation by nasal mask: technique and applications. Intensive Care Medicine, (1988) 14:115-117.
- Collopy, B., Dubler, N., and Zuckerman, C.: The ethics of home care: autonomy and accommodation. Hastings Center Report, (1990) 20: 1-16.
- Dail, C., Rodgers, M., Guess, V., Adkins, H.V.: Glossopharyngeal Breathing. (1979), The Professional Staff Association of the Rancho Los Amigos Hospital, Downey, CA; 57 pages.
- Donner, C.F., Howard, P. and Robert, D.: Patient selection and techniques for home mechanical ventilation. Monaldi Arch Chest Dis (1993) 48:40-47.
- Donner, C.F., Howard, P. and Robert, D.: Recommendations for home mechanical ventilation (Concensus Conference). Eur Resp Rev (1992) 2 (10) 303-434 [131 pages].
- Fischer, D. Armin: Poliomyelitis: Late respiratory complications and management. Orthopedics. (1985) 8:891-894.
- Gilgoff, I.S., et al.: Hypoventilation and Apnea in Children during Mechanically Assisted Ventilation. CHEST (1992) 101:1500-1506.
- Goldberg, A.I.: Pediatric High-Technology Homecare. *In*: Intensive Homcare, M.M.Rothkopf and J. Askanazi (Eds.), Williams & Wilkins, Baltimore (1992) Chapter 13, pp: 199-213.
- Goldblatt, D. and Greenlaw, J.: Starting and stopping the ventilator for patients with amyotrophic lateral sclerosis. Neurol Clin (1989) 7:789-806.
- Hill, N.S.: Clinical Applications of Body Ventilators. CHEST (1986) 90:897-905.
- Hodgkin, J.E., et al.: Pulmonary Rehabilitation, Guidelines to Success. (1984) Butterworth Publishers, Boston.
- Kacmarek, R.M. and Stoller, J.K.: Current Respiratory Therapy. (1988) B.C. Decker, Inc., Philadelphia.
- Kinnear, W.J.M. and Shneerson, J.M.: Assisted Ventilation at Home: Is It Worth Considering? (Review) Br.J.Dis.Chest (1985) 79:313-351.
- Levine, S., et al.: Negative-Pressure Ventilation, Critical Care Clinics (1990) 6:505-531.
- Leger, P. et al.: Home Positive Pressure Ventilation via Nasal Mask for Patients with Neuromuscular Weakness or Restrictive Lung or Chest-Wall Disease. Resp. Care (1989) 34:73-77.
- Mahlmeister, Michael J., et al.: Positive-Expiratory-Pressure Mask Therapy: Theoretical and Practical Considerations and a Review of the Literature. Resp.Care (1991) 36:1218-1230.
- Make, B.J. and Gilmartin, M.E.: Mechanical Ventilation in the Home. Critical Care Clinics (1990) 6:785-796.

- Marcy, T.W. and Loke, J.S.O.: Diaphragm Pacing for Ventilatory Insufficiency. J Intens Care Med (1987) 2:345-353.
- Marino, W.D. and Kvetan, V.: Home Positive Pressure Ventilatory Support. *In: Intensive Homecare*, M.M.Rothkopf and J. Askanazi (Eds.), Williams & Wilkins, Baltimore (1992) Chapter 11, pp: 159-171.
- McPherson, S.P.: Respiratory Home Care Equipment. (1988) Daedalus Enterprises, Inc. - Kendall/Hunt Publishing Co., Dubuque, Iowa. 182 pages.
- O'Donohue Jr., W.J., et al.: Long-term Mechanical Ventilation. Guidelines for management in the home and at alternate community sites. (Report of the Ad Hoc Comm., Resp. Care Section, American College of Chest Physicians.) CHEST (1986) 90 (Supplement): 1S-37S.
- O'Donohue Jr., W.J.: Prescribing Home Oxygen Therapy. What the Primary Care Physician Needs to Know. Arch Int Med (1992) 152:746-748.
- Preston, W., et al.: Managing Breathing Problems. Managing Amyotrophic Lateral Sclerosis Manual III. (1986), 104 pages. The ALS Association, 21021 Ventura Blvd., suite 321, Woodland Hills, Calif. 91364.
- Prentice, W.S., Wilms, D., and Harrison, L.B.: Outpatient management of ventilator-dependent patients. *In: Pulmonary Rehabilitation, Guidelines to Success*. Hodgkin, J.E., et al., (Eds.) Butterworth Publishers (1986), Boston. Chapter 19; pp: 323-351.
- Raffin, T.A., Shurkin, J.N. and Sinkler III, W.: Intensive Care. Facing the critical choices. (1989) W.H.Freeman and Company, New York, NY. 210 pages.
- Raffin, Thomas A.: Ethical Issues in Respiratory Care. *In: Foundations of Respiratory Care*. Pierson, D.J. and Kacmarek, R.M. (Eds.) Churchill Livingstone (1992) New York. Chapter 103; pp: 1213-1219.
- Rothkopf, M.M. and J. Askanazi (Eds.): Intensive Homecare. (1992) Williams & Wilkins, Baltimore, MD. 321 pages.
- Shneerson, J.M.: Noninvasive and domiciliary ventilation: negative pressure techniques. THORAX (1991) 46:131-135.
- Silverstein, M.D., et al.: Amyotrophic Lateral Sclerosis and Life-Sustaining Therapy: Patient's Desires for Information, Participation in Decision Making, and Life-Sustaining Therapy. Mayo Clin Proc (1991) 66:906-913.
- Spencer, G.T.: How to make a cuirass shell that works. Rehabilitation Gazette (1981) 24:49-50.
- Spencer, G.T.: Treatment of Underventilation By Day and Night. International Ventilator Users Network News. (1988) 2:3-5.
- Strumpf, D.A., et al. : Nocturnal Positive-Pressure Ventilation via Nasal Mask in Patients with Severe Chronic Obstructive Pulmonary Disease. Am Rev Respir Dis (1991) 144:1234-1239.

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- Strumpf, D.A., et al.: The Management of Chronic Hypoventilation. CHEST (1990) 98: 474-480.
- Strumpf, D.A., et al.: Nocturnal Positive Pressure Ventilation via Nasal Mask in Patients with Severe COPD. Am Rev Resp Dis (1991) 144:1234-1239.
- Sullivan, C.E., et al.: Reversal of obstructive sleep apnea by continuous positive airway pressure applied through the nares. Lancet (1981) 1:862-865.
- Tobin, M.J.: Weaning from Mechanical Ventilation. Current Pulmonology (1990) 11: 47-105.
- Willig, T.N., Robert, D., Paulus, J., and Leger, P.: Nasal Ventilation in Neuromuscular Disorders (International Conference) Eur Resp Rev (1993) 3 (12): 243-307 [64 pages].
- Wolf, C.R.: Respiratory Rehabilitation: A Practical Guide. (1986) Toronto General Hospital, 200 Elizabeth Street, Toronto, Ontario, Canada M5G 2C4.

- Advocacy Group for Ventilator Dependent People, 3352 Quail Run Road, Los Alamitos, California 90720.
- American Association for Respiratory Care, 11030 Ables Lane, Dallas, Texas 75229. (214) 243-2272.
- American Association of Retired Persons (AARP), Health Advocacy Services, 1909 K Street, NW; Washington, DC 20049. Many excellent publications and materials, many are free. Request catalog. Note: "Home is Where the Care Is" an audiocassette program for caregivers.
- American College of Chest Physicians, 3300 Dundee Road, Northbrook, IL 60062-2348. (708) 498-1400.
- ALS Association (Amyotrophic Lateral Sclerosis), 21021 Ventura Blvd., Suite 321; Woodland Hills, California 91364 (818) 340-7500 FAX: (818) 340-2060.
- American Lung Association & American Thoracic Society, 1740 Broadway, New York, N.Y. 10019-4374. (212) 315-8700 FAX: (212) 265-5642 - or:  
ALA of California, 424 Pendleton Way, Oakland, California 94621-2189 (510) 638-5864;  
ALA of Los Angeles County, PO Box 36926, Los Angeles, CA 90036-0926 (213) 935-5864.
- Association for Living Independently in a Ventilator Environment (ALIVE); 21027 Roscoe Blvd., #2, Canoga Park, California 91304. (818) 882-1733 or (213) 696-8165.
- Association Française contre les Myopathies (A.F.N.), Service des Affaires Médicales, B.P. 59, 1 rue de l'Internationale, F-91002 Evry Cedex, France. 011-33-(1) 69 47 28 28
- Association Nationale Pour Le Traitement á Domicile de L'Insuffisance Respiratoire Chronique (ANTADIR); 66, Boulevard Saint-Michel, 75006 Paris, France.
- California Self-Help Center, UCLA, Los Angeles (800) 222-LINK, (310) 825-1799.
- Concepts of Independence, Inc., 853 Broadway, Suite 1404, New York, N.Y. 10003; (212) 477-7600. A pioneering home care program for self-directed disabled people, 40 of whom use a ventilator at home.
- Independent Living centers: Independent Living Resource Center, 70 - 10th Street, San Francisco, CA 94103. Or, contact your local center - *such as*: the Westside Center for Independent Living, Los Angeles, California - telephone: (310) 390-3611.
- International Ventilator Users Network (I.V.U.N.): Also, Gazette International Networking Institute (GINI). 5100 Oakland Avenue, #206; Saint Louis, Missouri 63110. (314) 534-0475. An educational and support organizations for ventilator-users and professionals interested in home mechanical ventilation. Regular newsletters.
- March of Dimes Birth Defects Foundation, 502 South Verdugo Drive, Burbank, CA 91502-2344 (They support some *selected* respiratory equipment for post-polio survivors). (818) 956-7280.

Motor Neurone Disease Association, P.O. Box 246, Northampton NN1 2PR, England.  
011-44-604 250505.

Muscular Dystrophy Association — contact your local MDA office, *or* The MDA national office, 3561 East Sunrise Drive, Tucson, AZ 85718. (602) 529-2000.

National Center for Home Mechanical Ventilation, 1400 Jackson Street, J104; Denver, Colorado 80206. (303) 398-1949. A non-profit research organization whose goal is to improve the safety and efficacy of home mechanical ventilation.

National Council on Independent Living, 2539 Telegraph Avenue, Berkeley, California 94704. (415) 841-4775. *Or*: NCIL, Troy Atrium, 4th St. & Broadway, Troy, NY 12180. (518) 274-1979.

National Spinal Cord Association, 600 West Cummings Park, suite 2000; Woburn, Mass. 01801. (617) 935-2722. A membership consumer-based organization with local chapters.

Parents Helping Parents, Fountain Valley, California (408) 288-5010.

Polio Survivors Association, 12720 La Reina Avenue, Downey, CA 90242. (310) 862-4508.

Sick Kids need Involved People (S.K.I.P.), 216 Newport Drive, Severna Park, Maryland 21146 (301) 647-0164; *or*: SKIP of New York, 990 Second Avenue, #2., New York, N.Y. 10022; and many other chapters.

World Institute on Disability, 510 16th Street — Suite 100, Oakland, CA 94612-1502. 510-763-4100.

- Atomisor, La Diffusion Technique Française, 114 à 120 rue Bergson, B.P. 132, F-42003 Saint-Etienne Cedex 1, France. 011-33-77.74.51.11. Nasal mask for ventilation that fits into nose.
- Aequitron Medical, Inc., 14800 28th Avenue North, Minneapolis, MN 55447. (800) 497-4979; (800) 497-4968. Equipment including: LP6-plus and LP10 ventilators & accessories.
- Atrotech Company, P.O. Box 28, SF-33721 Tampere, Finland. [Medlink Technical Corp. distributor in the United States, P.O. Box 24805, Los Angeles, Calif. 90024 (213) 477-3696]. Equipment including: Atrostim phrenic nerve stimulation system.
- Avery Laboratories, Inc., 145 Rome St., Farmingdale, N.Y. 11735 - *now*: the Dobelle Institute, 100 Lattingtown Road, Glen Cove, N.Y. 11542-1243. (516) 676-9292. Equipment including: Diaphragmatic pacing equipment.
- Bear Medical Systems, Inc., 2085 Rustin Ave., Riverside, CA 92507. (714) 351-4849; (800) 331-2327. Equipment including: Bear 33 volume ventilator; venti-voice.
- Bird Products Corp., 3101 East Alejo Rd., P.O.Box 2007, Palm Springs, CA 92262. Equipment including: Bird and PortaBird ventilators, and Bird pneumobelt.
- Boehringer Laboratories, P.O. Box 870, Norristown, PA 19404. (800) 642-4945. Equipment including: bronchodilator "tee" - metered dose inhaler adapter.
- Breas Medical AB, Box 1410, S-400 20 Göteborg, Sweden. 011-46-(0)31-404-303. Equipment including: Homecare personal ventilator PV 501; and PV 201 for apnea sleep disorder treatment.
- Chest Scientific Instruments Ltd., 1, Concorde Business Park, Biggin Hill, Kent TN16 3YN, England. Telephone: 011-44-959-571259. Equipment including: Mouth Pressure Meter for assessment of respiratory muscle weakness.
- Churchill Ltd., (Toby Churchill) 20 Panton Street, Cambridge CB2 1HP, England. Telephone: 011-44-223-316117. Equipment including: Lightwriter computer based speech augmentation equipment, communication system and voice synthesizer, switches and accessories.
- DeVilbiss Health Care, Inc., P.O.Box 635, Somerset, PA 15501-0635. (814) 443-4881. Equipment including: nebulizers, suction, nasal CPAP, oxygen concentrators.
- Dräger Médical S.A., 5 bis, Avenue Maurice-Ravel, F-92168 Anthony Cedex, France. 011-33-1-46.66.70.50. Portable ventilator EV 800, for patient transportation and home use.
- J.H. Emerson Company, 22 Cottage Park Avenue, Cambridge, MA. 02140-1691. (800) 252-1414. Equipment including: In-Exsufflator cough machine; 33 CR & 33 CRE chest respirator pump; poncho type wrap for negative pressure ventilation.
- Instrumentation Industries, Inc., 2990 Industrial Blvd., Bethel Park, PA 15102. (800) 633-8577; (412) 854-1133. Equipment including: metered dose inhaler adapter, MDI port: RTC 21-D, 22-D, 23-D.

Healthdyne, Inc., 2253 Northwest Parkway, Marietta, GA 30067. (404) 955-9555. Nasal masks and nasal seal for CPAP and nasal IPPV.

Homedco, 17650 Newhope Street, Fountain Valley, Calif. 92706. (714) 755-5600. Services include: home respiratory therapy, home mechanical ventilation, durable medical equipment, oxygen and home infusion therapy. [Durable medical equipment company.]

LIFECARE International, Inc., 655 Aspen Ridge Drive, Lafayette, CO 80026-9341. (800) 669-9234; (303) 666-9234. Equipment including: Positive and negative pressure ventilators, Pulmo-wrap®, Nu-mo® garment, chest shells, Exsufflation belt, PVV, PLV-100 & PLV-102 ventilators; NEV-100 negative pressure ventilator, 170-C and RBL/Bantam ventilators; Emerson rocking bed; Emerson iron lung ventilator; CPAP-100; Lipseal®; mouthpieces; various masks for CPAP or nasal IPPV: Softwear Nasal Mask, Standard Custom Nasal Mask, as well as the Integral and Thermoformable Custom Nasal Masks.

Lyon nasal mask: a custom molded silicone mask on a thermoformable shell. Distributed by SEFAM in Europe, and by LIFECARE International, Inc. in the USA. Developed by Dr. Dominique Robert and Dr. Patrick Leger, Réanimation et d'Assistance Respiratoire, Hôpital de la Croix-Rousse; 93, Grande Rue de la Croix-Rousse, F-69317 LYON cédex 04, FRANCE.

Monaghan Medical Corp., P.O. Box 978, Plattsburgh, New York 12901-0978. (518) 561-7330; (800) 833-9653. Equipment including: AeroChamber, AeroVent; 179-C negative pressure ventilator.

Olympic Medical Corp.; 4400 Seventh South; Seattle, WA 98108. (800) 426-0353. Equipment including: Olympic Trach-Talk™ and Olympic Trach-Button™.

Passy & Passy Inc., 4521 Campus Drive, Suite 273; Irvine, California 92715. (800) 833-8299. Equipment including: Passy-Muir™ tracheostomy and ventilator speaking valves.

PneuPac Limited, Crescent Road, Luton Beds, LU2 0AH, England. Telephone: 011-44-582-453303. Equipment including: the BromptonPAC assistor-controller ventilator for home and hospital, designed for noninvasive nasal IPPV [not for life-support ventilation].

Porta-Lung: 401 East 80th Avenue; Denver, Colorado 80229. (303) 288-7575. Equipment including: Porta-Lung. [W.W. Sunny Weingarten]

Prentke Romich Company, Wooster, Ohio. Communication equipment, including the Liberator™.

Puritan Bennett Corp., Portable Ventilator Division; 4865 Sterling Drive; Boulder, Colorado 80301. (800) 248-8833; (913) 661-0444. Equipment including: Companion PB-2800, PB-2801, and PB-2500 portable ventilators; PB-Thompson M25B and PB-Thompson Maxivent portable ventilator; Pneumobelt; Porta-Lung; Companion ADAM circuit; "Turtle" chest shell; liquid oxygen systems - Mark 5 walker; mouthpieces; and nasal masks.

REMAFAE TECH, Pliggvägen 34, S-12639 Hägersten, Sweden. Equipment including: The Remmer Mask™; is a custom acrylic mask made in Hägersten, Sweden, from an impression of the patient's nose.



Respironics Inc., 1001 Murray Ridge Drive; Murryville, PA 15668-8550. (800) 638-8208; (412) 733-0200. Equipment including: BiPAP S/T<sup>®</sup> Ventilatory Support System; BiPAP-S<sup>®</sup> Airway Management System; contour nasal masks; and REMstar Choice<sup>®</sup> nasal-CPAP.

ResCare Inc., 6044 Cornerstone Court West, San Diego, CA 92121. (800) 424-0737. *Or in Australia:* ResCare Limited, 82 Waterloo Road, North Ryde NSW 2113, Australia. Equipment including: The Sullivan<sup>®</sup> APD 2 Nasal CPAP System series and accessories; and the Sullivan<sup>®</sup> Bubble Cushion nasal mask.

Société d'Etude et de Fabrication d'Appareillage Médical (SEFAM); Rue du Bois de la Champelle; F-54500 Vandœuvre-Les-Nancy; France. Equipment including: VENTIL+ bilevel ventilator for nasal IPPV; NASAL+ standard nasal masks; Custom formed nasal masks for nasal IPPV; and polysomnographic sleep study equipment. [U.S. distributor for the nasal masks: LIFECARE.]

Thomas Respiratory Systems, 33 Half Moon Lane, Herne Hill, London SE24 9JX, England. 011-44-071-737-5881. The Nippy<sup>™</sup> portable positive pressure ventilator.

VitalAire; 2121 N. California Blvd., Walnut Creek, CA 94596. (510) 977-6200. *In France:* 75 quai d'Orsay, F-75321 Paris cedex 07, France. Home respiratory care, durable medical equipment including: ventilators, respiratory equipment; compressed and liquid oxygen. International services. [Durable medical equipment company.]

Words +, Inc., P.O. Box 1229, Lancaster, Calif. 93584. (800) 869-8521. Equipment including: integrated computer access and augmentative communication equipment, voice synthesizers, infrared/sound/touch switch, and accessories.

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