UnMASKing the Issue: A Subjective Review of Seven Masks/Headgear

Audrey J. King, MA

Wouldn’t it be wonderful to find a nearby accessible “Mask and Headgear” store where every known interface for noninvasive ventilator users is on display, where staff are experienced, and the products are available for trial and purchase? Such is the dream of those who have struggled for years to find the right device. Noses and faces come in a zillion shapes and sizes but are harder to fit than feet. Thousands of well-stocked shoe stores exist, yet the common scenario when shopping for masks is to be offered one, perhaps two, by a therapist or vendor who does not have or may not even know all the options available.

Increasing use of CPAP and Bi-PAP units during the last 10 years by thousands of people with sleep-related breathing disorders has stimulated the development of many new masks and headgear. As long-term ventilator users, we need to know what the choices are.

Recent attendance at the Eighth International Conference on Post-Polio and Independent Living in Saint Louis provided an opportunity to see and compare several masks. I talked with ResMed, Respironics, and Mallinckrodt representatives and brought home a variety of their newer masks to evaluate.

Three post-polio nocturnal ventilator users, including me, tried and compared five new masks/headgear, as well as the ones we currently use. We were already mask users, having converted from negative pressure cuirass use years earlier. Allan Gouldburn and Sheila Keogh both use a standard Contour™ mask; Allan with a BiPAP® S/T since 1992, and Sheila with a PLV®-100 since 1988. I used a Contour™ mask with a PLV®-100 since 1992, but have preferred the Healthdyne Soft Series™ which I began using in 1994. (Healthdyne has since been acquired by Respironics.)

Our evaluations were limited by the size of mask provided and length of trial. It is difficult to persist with a device that is uncomfortable and disruptive to one’s sleep, especially if your current mask works well. Getting used to something new is like breaking in shoes: the longer you wear them the more you accommodate and the better you become at resolving some of the adjustment problems. It takes several weeks to fine-tune position, tightness, etc. In some cases, our opinions were based on only a few hours of use.

CAPS AND STRAPS. Limited arm function presents a challenge in managing and adjusting mask/headgear devices, especially in the middle of the night. Allan manages his mask/headgear independently, albeit with difficulty, but Sheila and I require total assistance. Over the years we all have found the Respironics Softcap™ to be the most suitable for getting on and off and for keeping the mask in place. I particularly like the Softcap™ with the clip fastener because you do not have to deal with Velcro once the straps are initially adjusted. The Ultra Mirage™ has similar release clip fasteners that are even easier to manage.

Mallinckrodt (800-497-4979; www.mallinckrodt.com)
Breeze™ SleepGearTM
Soft Fit™ Ultra
ResMed (800-424-0737; www.resmed.com)
Ultra Mirage™
Respironics (800-638-8208; www.respironics.com)
Contour (older mask)
Contour Deluxe™
Simplicity™
Soft Series™ (older mask)

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The newer masks (Simplicity™, Ultra Mirage™, and Contour Deluxe™) feature neoprene straps that are thicker, stretchy, and spongy. With the Simplicity™ and Contour Deluxe™, the user is supposed to be able to pull the headgear off and on (once the straps are adjusted) by stretching it over the head like a very tight toque or balaclava. Such maneuvers were not possible for any of us due to limited hand and arm function. The Velcro was difficult to unstick and the strap elasticity seemed to cause shifting and looseness.

The Simplicity™ has five straps rather than the usual four. This extra strap (which comes down from the forehead) simply added to the adjustment challenge and created no extra securement. We all found that the fifth strap would not stay in place.

The Breeze™ is a semi-rigid C-shaped piece which carries a narrower hose centrally from the back of the head to the nostrils and utilizes ADAM™ nasal pillows, thus combining interface and headgear in one. Once the straps on either side of the head from the back plate to the top of the head plate are set up, there are no other straps to deal with regularly.

The rigidity and absence of straps make it quick and easy to put on, but also make it less secure and difficult to keep in place. Allan and Sheila found this to be a problem, particularly Allan who moves in bed and gets up during the night. I solved this problem by attaching an extra ½-inch elastic strap to the side straps; a standard chinstrap can also be adapted.

The semi-rigidity of the Breeze™ headgear enabled me to easily re-adjust it with one hand by grasping the nasal part or by moving the back of my head against the stiff rear plate. Sheila found this rear piece uncomfortable to rest her head on for any length of time, perhaps because she sleeps with a pillow instead of a soft neck roll as I do.

CHEEKS AND LEAKS. People using ventilators have different pressure needs and different tolerances for leaks. In general, the higher the pressure needed, the tighter the mask needs to be and the greater the pressure exerted on the face.

We found that the Ultra Mirage™ and the Contour Deluxe™ bit into the cheeks. The regular Contour™ and Soft Series™ masks did not. The second membrane of the SoftFit™ Ultra, which inflates with each breath, was noticeably cushioning and did not leak or dig into the cheeks, providing a snugger and more comfortable fit. Sheila found this inflating feature, similar in the Simplicity™, to be comfortable at first, but bothersome with each breath after a while.

The Simplicity™, which is small, soft, and pliable, was satisfactory at first. However, its lack of rigid underframe required the mask to be secured more tightly in order to prevent leaks. Even when tightly secured, the Simplicity™ was difficult to keep in place and leaks occurred as it shifted.

The Breeze™, which uses ADAM™ pillows, does not rest on the cheeks at all. When the headgear shifts out of position, air leaks from the nostrils. Realigning the headgear, twisting the nasal pillows sideways, and using the proper size of pillows can help solve this problem.

Not all masks/headgear have rotating and/or swivel connectors. A rotating connector allows the hose to lie in any position. A swivel connector prevents the hose from twisting and causing leakage and pressure areas. These connectors are particularly important to those who move frequently or who do not have attendant assistance.

NOSE WOE. The bridge of the nose seems to universally take the most abuse when using mask ventilation. Allan’s nose is constantly red with a recurring scabby sore. Sheila’s nose is pink in the morning, but fades rapidly. Mine is red and indented for a few hours, but it is not sore and the skin has never broken down.

Allan thought he had a winner with the Contour Deluxe™ but after several nights of use the soreness returned. Although we liked its smaller size, Sheila and I were not able to use this mask for more than a few hours due to cheek pressure. However, there was no nose redness. Allan found some relief with the Simplicity™, but after several nights the pressure area simply moved further down his nose. I had the same problem.

The Ultra Mirage™ features an adjustable hinge that can be set to angle the pressure off the bridge of the nose. Allan liked this feature, but felt the adjustment didn’t have enough range. He would also like a more secure lock to eliminate any accidental
ALS Pulmonary Protocol

Ed White

In my opinion, it is important to introduce noninvasive mask ventilation when one's forced vital capacity (FVC) approaches 75%. This provides enough time for one to become familiar with the equipment and respiratory care. It took me about 90 days to get the equipment lined up and to find the masks that fit my needs. During this time my FVC dropped precipitously, and, in retrospect, I had waited too long to begin this process. The individual with ALS must stay ahead of the curve, and it is vital to be early rather than late. The road from neurology to pulmonology can be difficult to navigate; the transition from neurological care to pulmonary care can be complicated.

I currently use nasal ventilation with a volume ventilator (PLV®-100) and the BiPAP® S/TD-30. Both are from Respironics (www.respironics.com). For daytime use, I have combined the volume ventilator and BiPAP unit into a single integrated system utilizing one-way valves and modifications to all the masks to take advantage of the ventilator's exhaust system for both pieces of equipment. This enables easily switching from the volume ventilator to BiPAP with the flick of two switches.

I believe that the volume ventilator and BiPAP unit each has unique advantages and that certain synergistic effects occur when both are used. The ventilator provides better respiratory support and lung expansion than BiPAP so I use it primarily during the day with some intermittent BiPAP use. However, I find BiPAP more comfortable at night and more sensitive as my breathing becomes more shallow.

Current settings for the PLV®-100: tidal volume of 1.25 liters, inspiratory pressure of 20-22 cm of H2O. (In my case, I seem to like a lot of pressure.) I have used Respironics' Monarch™ mask for about four years, and when I switch to BiPAP during the day, I continue to use it.

Current settings for BiPAP: tidal volume of about 1.2 liters, inspiratory pressure about 20 cm H2O, expiratory pressure 3-4 cm H2O, and breaths per minute about 10. I use nasal pillows with the BiPAP unit during the night, plus an in-line humidifier.

I have a pulse oximeter to monitor O2 saturation levels and pulse rate and a capnometer to spot check CO2 levels. At times an arterial blood gas test is needed for more precise measurement. With either analysis I find I am probably somewhat over-ventilated and experience some hypocapnea with low CO2 levels in the range of 30-32%.

For breathing on my own and to assist in coughing, I reconfigured an Ambu bag (www.ambusa.com) with an 18-inch tube and mouth-piece. Compressions on the Ambu bag result in air stacking which enables the lungs to expand and is a valuable aid for coughing. Occasionally I need more coughing assistance, and then I use the In-Exsufflator cough machine (www.jhemerson.com). It takes some time to become familiar with the In-Exsufflator, but it can be invaluable during respiratory infections.

When traveling, I use Respironics' BiPAP® Duet® unit which is marketed as a CPAP unit. This unit is very light and compact, but it provides the inspiratory pressure I require and can easily be adapted to a vehicle's power source.

Following this protocol allows me to monitor my respiratory status to gain a clear picture about my condition and any trends that might be developing. I urge others with ALS to start early to improve the quality of their lives. Early intervention helps one to evaluate future respiratory options, such as a tracheostomy, and is critical in avoiding a crisis situation. Preplanning makes me more com-

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I am the Coordinator of the HiTeC (High Technology Children) Program of the Xavier Children's Support Network in Brisbane, a community-based organization supporting families caring for their children with high medical needs at home. Most of the children are under 3 years of age and have life-limiting conditions.

My job is to coordinate the medical care for the children, supervise the staff, and provide training. I am also responsible for the equipment and medical stores. The team involved with the success of the program includes Judy Briggs, Senior Project Officer for High Cost Home Support Program (HCHSP); Sue Nancarrow, RN, my manager; all of the in-home staff; and, of course, the children and their families.

About two years ago, The Mater Children's Hospital approached Xavier to consider taking on an 18-month-old child with pulmonary hypoplasia who was ventilator-assisted and oxygen dependent with no chance of going home without support. With funding from the Mater for staff and a lot of fundraising by the parents, Betty came home and progressed beyond all expectations.

A short time later, the Royal Children's Hospital approached Xavier because they had two children using long-term ventilation ready to go home with support. Funding came from the HCHSP and Queensland statewide and non-governmental health services. The HCHSP now provides funding for three children in our program as well as a small number of adults, with demand growing rapidly.

Taking Jessie and Taylor home was a long and difficult process. We had to employ staff (a combination of experienced RNs and trained caregivers working together as a team), train them, and obtain all the equipment required. The families had full say in whom we employed, but the family home now became a workplace and had to meet all the necessary requirements as such.

Jessie at the time was 2 years old, with congenital myopathy of unknown aetiology. Taylor, now 4 years old, is quadriplegic, and the staff required a lot of training in his care. This was made easier by the fact that Taylor, who was paralyzed at 18 months, has the most wonderful personality and enjoyed all the attention.

Both boys use a PLV®-102 (www.respironics.com) ventilator with a Bivona FlexTend™ (www.bivona.com) tracheostomy tube. Betty uses a BiPAP® Vision™ (www.respironics.com) and nocturnal heated humidification with a Bivona standard cuffless tracheostomy tube. All the children have tried the Passy-Muir Tracheostomy Speaking Valve (www.passy-muir.com) but none likes to use it.

I would like to think that most of the children in our program will require very little assistance from us in the future. They have progressed rapidly since they went home which is a great credit to the families and the staff. Betty and Jessie are both walking. Their hospital re-admissions are few and far between and their dependence on the ventilator is lessening.

Taylor will be with us until he grows out of the children's service. It will be difficult, but his personality and his determination will help him make it that far. His mother holds the hope that one day Taylor will walk again. I think the hospital staff are surprised that Taylor has had so few hospital admissions over the last year, but they now trust us to care for him.

Our goal is to enable the families of the children to be more in control and to allow the next ventilator-assisted child in Brisbane to leave hospital more quickly. The IVUN has been a great source of reference and one through which I would like to link our families with others who have ventilator-assisted children.

ADDRESS: Margarette Somerville, RN, RSCN, HiTeC Coordinator, Xavier Children's Support Network, 284 Pine Mountain Road, Mt Gravatt East, Brisbane, Queensland 4122 Australia (+61 7 3216 8811; +61 7 3216 8778 fax; margarettes@xcsn.org).
Tracheostomy or Noninvasive Ventilation?

E.A. Oppenheimer, MD

Adapted from a presentation during GINI's Eighth International Post-Polio and Independent Living Conference, June 8-10, 2000, Saint Louis, Missouri

Who decides whether to use non-invasive (NPPV) or tracheostomy positive pressure ventilation (TPPV) in respiratory polio survivors and individuals with other long-term neuromuscular diseases and conditions such as ALS, SMA, or muscular dystrophy? You, the individual, should have an important say, but you should collect very good information based on your clinical condition, the clinical experience and advice of your physician, the risks and benefits of each method, and your goals and quality of life issues.

Indications for tracheostomy are primarily the failure of NPPV, excessive secretions, facial trauma, or upper airway obstruction that would not allow for NPPV. NPPV may eventually fail in people with post-polio because of difficulty clearing secretions, need to use the ventilator up to 24 hours daily, discomfort with a mask constantly on your face, work of breathing difficulty, and/or a desire for more efficient and safer equipment.

Sometimes ill-informed decisions about tracheostomy are made because people (both health professional and patient) believe they will no longer be able to speak and communicate. Indeed, the loss of oral communication can occur with tracheostomy, because air cannot get up to the vocal cords to enable speech if a tracheostomy tube with an inflated cuff is used. Speech is possible by using a deflated or cuffless tracheostomy tube, by adjusting the ventilator to obtain enough air flow for speech, or by using a cuffless tube with a Passy-Muir (P-M) Tracheostomy Speaking Valve (www.passy-muir.com).

Eating and swallowing can cause problems because tracheostomy decreases the mobility of the trachea. If the cuff is inflated, there is a pressure effect on swallowing and esophageal function, but use of a cuffless tube and the P-M valve facilitates swallowing. Taste and smell and humidification bypass the nose and upper airway with a tracheostomy tube if the tracheostomy cuff is inflated.

With NPPV, there is no incision to become infected. Infection is more common with tracheostomy due to the incision (stoma) allowing bacteria direct access to lower airways. During the first year, there is a certain amount of inflammation as the stoma goes through a healing process. Sometimes excessive proliferation (granulation tissue) accumulates inside the stoma and may need to be removed by a head and neck surgeon.

To decrease the risk of infection with tracheostomy: Avoid H2 blockers, such as Tagamet. Use only clean suctioning equipment and consider using a closed suctioning system. Dry everything. Use liquid nebulizers only if necessary (metered-dose inhalers are better), avoid using wet systems that can transmit infections. Use a humidifier only if necessary; a heat-moisture exchanger may be safer.

The presence of other lung diseases may influence the choice of tracheostomy over NPPV, such as vocal cord or upper airway problems, COPD, bronchiectasis, etc. If an upper airway obstruction is making NPPV difficult, tracheostomy avoids that problem.

Respiratory care is more complicated in TPPV due to stoma care and increased secretions with tracheostomy, as well as the need for suctioning or use of assisted coughing techniques (manual or mechanical).

Assisted coughing techniques are essential in NPPV to eliminate secretions, e.g. the huff and squeeze technique; augmenting volume by glossopharyngeal (frog) breathing; manually assisted techniques, such as abdominal thrusts, percussion, postural drainage; and mechanical assist devices such as the In-Exsufflator (www.jhemerson.com).

Mobility and independence may be more complicated with tracheostomy depending on how individuals manage their equipment and supplies. Portable suctioning equipment is usually necessary. Preferred for tracheostomy use, the volume ventilator, such as the PLV®-100 (www.respironics.com), is usually heavier and involves batteries. Back-up battery operation is a standard safety and convenience function with TPPV, but not with the bi-level positive airway pressure units generally used for NPPV.

However, newer ventilators, such as the Achieva™ (www.mallinckrodt.com) and LTV™
series (www.pulmonetic.com), allow various modes, include excellent alarms, and can be used for both NPPV and TPPV. The difference between the bi-level units and the volume ventilators may become history. Unfortunately, due to the higher cost of a volume ventilator, most people may have to choose between a bi-level unit and a volume ventilator. Some people having difficulty using a bi-level unit for NPPV may do better with a volume ventilator and not need to give up on NPPV.

If used for 24 hours, NPPV can require multiple interfaces and ventilators, and safety becomes an issue. One-third of all long-term ventilator users are 24-hour ventilator users. TPPV may be better and safer for 24-hour use due to improved alarms on the volume ventilators, more secure connection with the interface, and built-in battery. The face is free, and TPPV can be more comfortable. TPPV can also provide better ventilation with more volume than NPPV and breath stacking to improve cough.

Considerations of tracheostomy instead of NPPV must involve the physiological, medical aspects, such as bulbar functions and elimination of secretions; and personal choice. If NPPV is failing, then tracheostomy is necessary. The skill of the head and neck surgeon performing the tracheotomy is important. The wishes of the patient should be based on information and not fear, as well as family support and availability of equipment and other resources.

The cost of equipment and supplies, as well as nursing or attendant care is more expensive with tracheostomy. Many people are afraid of burdening their families with home care and they fear institutionalization. In the Scandinavian countries, the choice of tracheostomy is an easier one, due to their social services system that can provide 24-hour “home helper” attendant care.

A trial of NPPV can be initiated at home, and it is easy to stop if the person no longer wishes to use it. It is a useful decision-making tool for anyone new to mechanical ventilation, and better than making a decision in a crisis situation. A trial with TPPV is obviously not possible, and stopping TPPV is more complex. Using NPPV can avoid emergency hospitalization due to sepsis, aspiration, and respiratory failure. Planning an elective hospital admission for tracheostomy also avoids a crisis situation, but it still requires a hospital stay for the procedure and training afterward. Collaborative decision-making requires good information and discussion between the individual and the physician.

ADDRESS: E.A. Oppenheimer, MD, FCCP, Pulmonary Medicine, Los Angeles, California (eaopp@ucla.edu).

Cuffed Or Uncuffed Tracheostomy Tubes in ALS

I have used both cuffed and uncuffed trach tubes, but found that the cuffed trach caused me to produce more secretions, even when the cuff was deflated during the day. I needed suctioning about every 15 minutes except when asleep. With the uncuffed trach, I only need suctioning a couple of times in the morning, sometimes not at all.

However, an uncuffed trach has its own problems. At night I would wake up disoriented and with a headache, signs of under-ventilation. I was losing air out my nose while I slept, which an cuffed trach prevents. The solution was to wear swimmer’s nose plugs at night. I wear gauze pads on the nose plugs to prevent pressure sores, and my nurse rubs A & D ointment into my nose each morning. Sometimes the plugs move during the night and I have to have someone adjust them. A warning to anyone who uses Robinal to reduce secretions: be aware that it may dry out the intestines as well and may cause constipation.

ADDRESS: Wayne Phillips (wsphillips@compuserve.com; www.redrival.com/wsphillips/tpals.htm)
Skydiving Quad

Ola Grind Hermo

I am 34 years old and became a 24-hour ventilator user after breaking my neck (C-4) by diving into shallow water in De Land, Florida, on October 1, 1993. I was team captain of the Norwegian national team in 8-way formation skydiving. We had been at Skydive De Land in Florida near Daytona Beach (the best place to jump in the U.S. and where the tandem jump was born), training for the upcoming U.S. nationals competition. We were the first team to offer the French, Russian, and U.S. teams a proper challenge and were bound for Arizona the next day for the World Meet. That night I broke my neck by diving into shallow water. (My team had to leave for Arizona without me. They fought for the gold medal, but placed fourth.)

I was treated at Halifax Medical Hospital in Daytona Beach for two weeks before a Norwegian air ambulance could take me back to Norway. I was trached and used a Shiley tube (www.mallinckrodt.com) until I switched to a Bivona trach tube (www.bivona.com) in 1995. I change the trach tube every morning and have not had any respiratory infections or pneumonias.

On July 21, 2000, I became the first person in the world (according to the Guinness Book of Records) to make a tandem jump from an altitude of 18,000 feet over Østre Aera, the center for skydiving in Norway. My friends from Norway and Sweden built a 35-way formation around me and my tandem pilot who had been my partner before the accident. We used oxygen from 10,000 feet until 18,000 feet. My tandem jump was so perfect — it is difficult for me as an older, full-time, fully dedicated skydiver to describe for other people what the experience meant for me, especially in English.

The jump would not have been possible without the LTV1000™ (www.pulmonetic.com). I had used the PLV®-100 (www.respironics.com) until then. I strapped the LTV1000™ to my body under my jumpsuit and it worked beautifully. I am most grateful for this new, small ventilator, made by Pulmonetic Systems. Now I and other people with disabilities can set ourselves new goals and break old records.

ADDRESS: Ola Grind Hermo, Stremehagaen 11, N-7460 Røros, Norway (oghermo@online.no).

EDITOR'S NOTE: Randy Haims, C-2 quad, skydove from an altitude of 12,500 ft. His story "Air scuba ... or I can't walk but I can fly" appeared in IVUN News, Fall 1993. It can be read online at www.post-polio.org/ivun.html.

I am now in my eighth year with ALS, half of that time spent using nasal ventilation. I have not had any respiratory infections for over five years. I attribute this to my pulmonary protocol, attention to detail, and an aggressive program of vitamins and supplements which have greatly improved my immune system. It is somewhat oxymoronic, but in many ways I have never been healthier than with ALS.

ADDRESS: Ed White, P.O. Box 759, Fredericksburg TX 78624 (elwhldns@ktc.com).

Calendar 2001


MARCH 7-9. Eighth International Conference on Home Mechanical Ventilation, Lyon, France. Journées Internationales de Ventilation à Domicile (JIVD), Hôpital de la Croix-Rousse, Service de Réanimation Médicale et d'Assistance Respiratoire, 93 Grande-Rue de la Croix-Rousse, F-69317 Lyon Cedex 04, France. (+33 4 78 39 08 43 phone; +33 4 78 39 58 63 fax; www.jivd-france.com; BrigitteHautier_JIVD@compuserve.com)

MAY 2-3. Beyond Ventilation: A Meeting of the Minds. Toronto Congress Centre, Toronto, Canada. Contact Marg Wagner, Citizens for Independence in Living and Breathing, 55 Greenwood Court, Kitchener, Ontario, N2N 3H6 Canada (519-570-9713 phone and fax; cilb@idirect.com).
angle changes. I found the adjustment merely transferred pressure from my nose to my upper lip and forehead. Sheila felt the mask was big, bulky, and extended too high on her forehead.

Although impressed overall with the comfort of the Soft Fit™ Ultra, similar to the Soft Series™, my nose was still red in the morning as was my forehead where the spacer rested. Sheila’s nose became extremely red and sore. Pressure on the bridge of the nose is eliminated with the Breeze™ because it does not rest on the face at all. Sheila, who has high pressure needs, found the direct force of air into her nostrils painful. For me, the air delivery felt more like normal breathing than with a mask and similar to the more direct air delivery I experienced when ventilated via tracheostomy last year. Allan was not happy with the nasal prongs and the weight of the Breeze™ tubing.

**COSMETIC COMFORT.** I have used the Breeze™ continuously since June and will continue to do so unless problems, such as cold sores, necessitate a return to my Soft Series™ mask. I believe it is important to have an alternative back-up system. I like the openness, freedom, ease of use, and modern non-medical look of the Breeze™.

Allan liked the SoftFit™ Ultra and intends to use it regularly. He is pleased to have found a mask which will resolve his nose soreness once he establishes the right degree of strap tightness and connects a swivel adapter to stop hose twisting.

Sheila will continue to use her standard Contour™ mask which has proven problem-free for many years.

We have greatly appreciated the opportunity to try a variety of masks and headgear and thank Mallinckrodt, ResMed, and Respironics for their generosity in providing them. We would be pleased to share our ideas further. And we did come close to finding that imaginary “Mask and Headgear” store at www.cpapplus.com.

Contacts:
Allan Gouldburn (algee@idirect.com);
Sheila Keogh (bskeogh@home.com);
Audrey King (kingaj@istar.ca).