The Tank Collar: I understand Lifecare (303/666-9234) and other sources report that sponge tank collars last only 3-4 days. However, they have found a somewhat primitive way to extend the life of the collar a bit longer. Here is what they advise:

Get a one-pound empty coffee can, approximately four inches in diameter and file the edges of the can until it is sharp enough for cutting. Place the can directly over the center of the hole in the neck collar (you will have to take it off the iron lung first,) and slowly twist the can until it cuts through the collar making a larger hole, (very much like a cookie cutter.) Now when you pull the straps through evenly, you have a larger opening and, thus, it will be less likely to tear.

A more practical solution is the newer yellow twist collar. It opens up wide by twisting it until it becomes perfectly straight, (much like the shutter opening of a camera,) allowing greater head and nose clearance. Get a 4" x 16" foam rubber tank collar (obtainable at TIRR and Lifecare) and cover it with a length of 4" x 16" Stockinett tubing, like a sleeve. The TIRR collars are 4" wide, whereas the Lifecare collars are 2" to 3" wide. This is good to know if you have a long, thin neck or a short, fat one. Wrap this around the neck, securing or fastening it either with Velcro or a large safety pin or two. When that's snug and secure, push the yellow collar in all the way around the neck and begin twisting or turning the ring which turns the yellow collar tighter, until it twists closed, eliminating air leaks or blowing air. (At times, inserting and running two fingers around the edge of
the collar gets rid of tiny leaks and annoying air blowing.) Sometimes, a hand towel, folded twice, the long way, and wrapped around your collar on the inside, also stops air leaks. My best advice to you is to experiment and try a variety of things. You may find a better way yourself. If you have a trach, Lifecare can provide you with a “trach bar.”

The yellow twist collar is very expensive initially, but would save you a lot of money and aggravation in the long run. The collar assembly costs $514 including an extra collar, which costs $19. You will have to add shipping charges, approximately $35. (It will weigh about 8 - 8-1/2 lbs.) I really think that this is the best solution. I've had mine for more than three years and have only replaced the collar once or twice.

The Tank Bed: I would recommend the following for your comfort: Have satin sheets and draw sheets made and be sure the tank sheet fits tightly. Have elastic put in around the edges of the sheet and/or straps added to secure it tightly under the mattress.

To Adjust the Tank Bed: There are three black wheels located under the head rest. The center wheel raises and lowers the head. By turning the two outer wheels at the same time and in the same direction, you can raise or lower the shoulder part of the tank bed. This positions your head higher or lower inside the tank collar and sometimes helps to stop leaks around the collar. These same two outer wheels, turned separately, will tilt the tank bed to the left or to the right. (This is good for drainage of congestion or repositioning after long periods in the tank.)

Foot Rest: These are hard to obtain, and the few that are left are used, but worth having. If none are available, have a carpenter connect two pieces of plywood with L-angles, so the two pieces of wood are at right angles. Slip one piece under the foot of the tank mattress and the other will stand up to support your feet or keep pillows from falling off the end of the tank bed.

Positive Pressure Vent: This is located at the upper back end of the tank. It is usually kept open, but for additional positive pressure, used to assist in coughing, simply turn the screw until the metal flap closes. This induces more pressure in exhaling. Use only as needed.

Trendelenburg: For drainage of chest congestion and for a foot-up/head-down position. The tank has a crank and handle on the right side, just under the motor with which to “jack up” the foot. This works hydraulically and should be fairly easy to do. For more complete details, check with your Lifecare representative or a respiratory therapist.

Nita Weil has been a ventilator user because of polio since 1952 at age 22. By day, she uses a pneumobelt. By night, she used a chestshell until four years ago when she returned to sleeping in an iron lung. She is Director of Volunteers at The Institute for Rehabilitation and Research, 1333 Moursund Street, Houston, Texas 77030. She lives in a nearby apartment with an attendant. She directs more than 90 volunteers who give 20,000 hours a year. She has organized fundraising activities that have earned more than $1 million. Over the years she has received dozens of awards, plaques, and citations, including the Governor's Award for Outstanding Volunteer Service.
EMERSON IRON LUNG

1. Hand operation handle
2. Connecting rod
3. Hand operation lever
4. Respiration rate adjustment
5. Negative pressure adjustment
6. Auxiliary electric outlets
7. Motor switch
8. Light switch
9. Positive pressure adjustment
10. Tilting jack valve
11. Tilting jack handle
12. Head-rest adjustment
13. Bed height adjustments
14. Socket for intravenous rod
15. Pressure gauge
16. Instruction panel
17. Alarm (not provided)
18. Dome pressure gauge (delete)
19. Intravenous tube opening and stopper
20. Mirror and book-rest supports
21. Collar clamp ring
22. Collar expanding straps
23. Head-end closing clamps
24. Location of aspirator jar (delete)

IRON LUNG OPERATOR'S INSTRUCTIONS

Available from Lifecare, 655 Aspen Ridge Road Road, Lafayette, CO 80026. These detailed instructions include: Checking for Leakage, Installing Lifecare Spiral Collars on Iron Lung Spiraltwist Collar assemblies, Instructions for Installing Drive Belt on Emerson Iron Lung (Adult, Youth, Infant), Maintenance Instructions for (Lubricating) Emerson Lung (Adult & Youth Models), Installing a Head End Gasket, and Procedure for Coughing Patient in Iron Lung.
LIFE AFTER LUNG

by Marsha Ballard

I have two college degrees, three kids and ten and a half years teaching experience in science and math.

I had both bulbar and spinal polio when I was 10. I was able to cope on a reasonably normal level until my middle thirties. Then several things hit my husband and me at once. We had money problems and illness followed by two years of very difficult teaching situations. I was constantly short-winded with a little hacking cough that never accomplished much. By the summer of 1975 I was desperate. I was coming apart at the seams! I was nervous as a cat, bursting into tears over everything. At impossible moments, I lost bladder control. Stairs and walking half a block were almost beyond me. We had to find new jobs for the next school year.

I got an appointment to see a gynecologist and my orthopedist from 20 years before. Both doctors took one look and referred me to the pulmonary specialist. He in turn sent me to TIRR in Houston to investigate the possibility of getting an iron lung to sleep in at home.

Going back to the lung required drastic changes in our lifestyle. My husband and I had never even considered trading our double bed for separate ones, and we had always done a lot of camping in the summers in our Volkswagen camper. A 700-pound monster would not fit in most bedrooms and made trips impossible.

On the other hand, my sons were just entering their teens. In the way of most boys that age, they challenged the world -- and most of all their father -- testing all the possibilities of their new size and maturity. My daughter was not yet four, still almost a baby. And, most of all, Wes, my husband needed me. In a peculiar way I have always been a strong force in our family, able to think of possible solutions when disaster hits, able to negotiate between warring members, willing to cope with the mundane necessities of balancing checkbooks, paying bills, and figuring taxes.

At first, claustrophobia and the feeling of helplessness in the lung nearly drove me up a wall. I would take some chloral hydrate to make me sleep, but when it wore off in the middle of the night, I had to get out. I even insisted on having an alarm bell put on the lung, just in case no one was close enough to hear me yelling.

Even at that, from the very first night, the lung was an enormous relief. Instead of getting up to go to the bathroom three and four times a night and waking up short of breath seemingly every few minutes, suddenly I felt good again! I could even scrub floors and climb stairs. My nervousness disappeared, and I took in my stride the stress of going into business for myself, and coping with all the day-to-day problems of a family.

My husband had greater difficulty. He had been less conscious of how desperate my physical problems had become, and lying in that big empty bed listening to the wheeze and grind of the lung brought out all of the basic loneliness of life. It was not the best way to contemplate your 40th birthday.

Fortunately, right about then, we went to a marriage encounter
weekend. The communication we established has enriched our relationship. We have always had a good marriage, but understanding each other has made it better. The fact of the lung is something we live with. It beats the alternative.

Several years ago, I started noticing that, even in the lung, I would wake up short of breath. Apparently, my throat would close while I was asleep. It may be associated with stress and worry, but is basically a physical thing, and this last year it got worse. I started having to get up more at night to go to the bathroom, and I would be more tired in the afternoons. Also, I would be panting even from walking a few steps, and I almost gave up grocery shopping and going to the mall.

I went back to TIRR. (I could travel because my father had bought a Porta-Lung, a fiberglass tank that fits in a camper.) After an evaluation, Dr. Vallbona decided I should cut down on my physical exertion, particularly step-climbing and excessive walking, and then try a C-PAP in addition to the lung at night.

Well, we did get our boys raised, and my daughter is now in college. This is a great deal more than I ever expected, but I've got some more things I want to do, now, particularly write books. That being the case, I've learned to tolerate the C-PAP. In fact, since I've been sleeping in the C-PAP and lung combination, I don't have to get up at all at night and I feel much better during the day. It even seems I am able to breathe deeper. Dr. Vallbona was pleased by the lower CO2 in my blood, too.

Looking back, I only wish I had gone to the lung earlier. Those last two terrible years teaching would have gone so much easier. I know the choking and bronchitis were directly related to breathing problems and fatigue from insufficient sleep. Perhaps if they would build lungs with inside controls for the collar and inside latches like the one rigged on mine now, people who are functional like me would not put off using a lung so long that they damage themselves.

Believe me, there is "life after lung." In the 12 plus years I've been sleeping in an iron lung, I have (1) nurtured my sons and daughter to the point that they are basically independent, (2) taught night school at the junior college, (3) taken a job as an employment counselor for a private agency and won best counselor for three months in a row, (4) opened and run my own employment agency, (5) written three books and a screenplay.

That is not to say these are fantastic accomplishments, but I've enjoyed them. I have also been by my husband as we faced a tornado that ripped the roof off our house, a fire that burned my office building, six wrecks involving family members, two moves, various crises in his job, and a great deal of time with just the two of us, lovers, working now on our 30th year of marriage. If it hadn't been for the lung, I'd have missed all this.

Address: Marsha Ballard, Ballard Employment Service, 401 E. Front, Suite 121, Tyler, TX 75702.
USER'S VIDEOTAPE OF AEQUITRON'S LP6

Jerry Daniel who has been disabled by respiratory polio since 1948 and who has used a volume ventilator for many years, is featured in the new clinician's and user's instructional videotapes made for the Aequitron Medical LP6 Volume Ventilator.

The videos were taped in a realistic home situation. "It was an interesting experience," Jerry said. "Of course, all I had to do was act like a patient on a ventilator, which was easy enough, since I am one."

In the videos, Jerry discusses learning to breathe with ventilator assistance and many important concerns, such as being prepared with backup battery power in case of a power outage.

Jerry, who is 51, has been disabled since age 11. He breathes without a ventilator for much of the day and he uses a ventilator for sleep and brief rest periods.

He runs Ven-Tek, his own ventilator repair business in his home and works for several West Coast homecare dealers specializing in early Life Products models LP3 and LP4 ventilators.

Address: Jerry Daniel, 4604 Plomodon, Vancouver, WA 98661.

The two training videotapes are available from Aequitron Medical, Inc., 14800 Avenue North, Minneapolis, MN 55441. Phone: (612) 557-9200. The 17-minute user's video is a basic, ventilator introduction for users and their caregivers. The 37-minute clinician's video covers the LP6 theory of operation, setting parameters and modes, and installation in a homecare situation. Each program is designed to be used with an Aequitron LP6 manual. Both emphasize alarm response and power alternatives. Manual and either videotape cost $24.

In addition to the tapes, Aequitron publishes a free quarterly newsletter of interest to both users and clinicians.

ENGLISH RESEARCH

THE LATE SEQUELAE OF POLIOMYELITIS

R.S. Howard, C.M. Wiles, and G.T. Spencer

Quarterly Journal of Medicine, New Series 66, No. 251, pp. 219-232, March 1988

Address correspondence and requests for reprints to Dr. G.T. Spencer, Phipps Respiratory Unit, St. Thomas' Hospital, London SE1 7EH, England

"Progressive functional deterioration following poliomyelitis has been reported after a prolonged period of stability. We present follow up data on 209 patients; the period from the original illness to December 1985 or death was between two and 73 years (mean 33.9.)

"One hundred and sixty-three (78 per cent) patients developed late functional deterioration. This was due to purely respiratory factors in 99 cases, new neurological signs in 20 cases, and orthopaedic problems in 17 cases; 31 patients deteriorated due to a combination of factors. The commonest cause of respiratory deterioration was the development of nocturnal alveolar hypoventilation, sometimes associated with late progressive scoliosis. Eighty-six patients needed respiratory support beginning between one year and 66 years (mean 28.5) after the acute illness. New neurological signs had a clearly defined cause in each of 20 patients. No cases of motor neurone disease or post-poliomyelitis muscular atrophy (PPMA) were identified.

"This series shows that late sequelae following poliomyelitis are common. There were no patients with functional deterioration after poliomyelitis in whom a clear underlying cause could not be shown. The major causes of deterioration may be treatable or avoidable, and in particular, those who develop chest infections or new respiratory
symptoms should be treated with caution as respiratory failure may rapidly supervene.

NONINVASIVE POSITIVE PRESSURE VENTILATION BY FACE MASK OR NOSE

POSITIVE PRESSURE FACE MASKS

Bud Blitzer 400 South Saltair Ave., Los Angeles, CA 90049.

"As you may recall from my past bulletins, we are trying to speed up the development of better face masks designed to meet the special requirements of ventilator users, especially when these masks could serve as a viable option to having a tracheostomy.

"We continue to make progress. Two manufacturers now have active product development programs underway, each with a different approach. In addition, there are several custom approaches including a new one I have been using myself for the past few months (while I consider this mask successful, I think it still needs some refinement before it gets released for general sale.)

"While we can't yet give you a phone number you can call to order yourself a mask, we're getting closer. Meanwhile, if your need is urgent, there is a phone number. Call me (213/476-9343) and I'll put you in direct touch with whomever seems best able to fill your needs at that time."

NASAL INTERMITTENT POSITIVE PRESSURE VENTILATION IN NOCTURNAL VENTILATOR DEPENDENT PATIENTS WITH MUSCULOSKELETAL DISORDERS


"We have used nasal ventilation since 1985 for chronically insufficient respiratory patients with musculoskeletal disorders.

"We have designed our own nasal mask. It is made to measure, by modelling silicon paste onto the patient's nose. This mask is more comfortable and there are less air leaks. The patients used ventilation every night, for an average of nine hours.

"The respirator settings are very similar to those used for artificial ventilation. These are adjusted depending on night recordings of SaO2.

"This method is efficient. The overall condition of the patients is better and their arterial blood gases improved significantly, allowing them to do more daily activities.

"But it requires a lot of caution and a strict and regular supervision. Because if nasal ventilation proves to be insufficient, tracheostomy and ventilation can still be performed and remain an efficient method."

LONG TERM FOLLOWUP OF PATIENTS ON NASAL ASSISTED VENTILATION DURING SLEEP

E.R. Ellis and C.E. Sullivan, Dept. of Medicine, Sydney University and the Sleep Unit, Royal Prince Alfred Hospital, Sydney NSW, Australia

LIVING AND TRAVELING WITH VENTILATORS

In the enclosed list of back issues and the current issue of the Rehabilitation Gazette are many informative and valuable articles of subjective experiences and adapted equipment. Look carefully at the articles under "Travel" and "Ventilation/Ventilators," as well as under "Equipment" and "Polio."
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