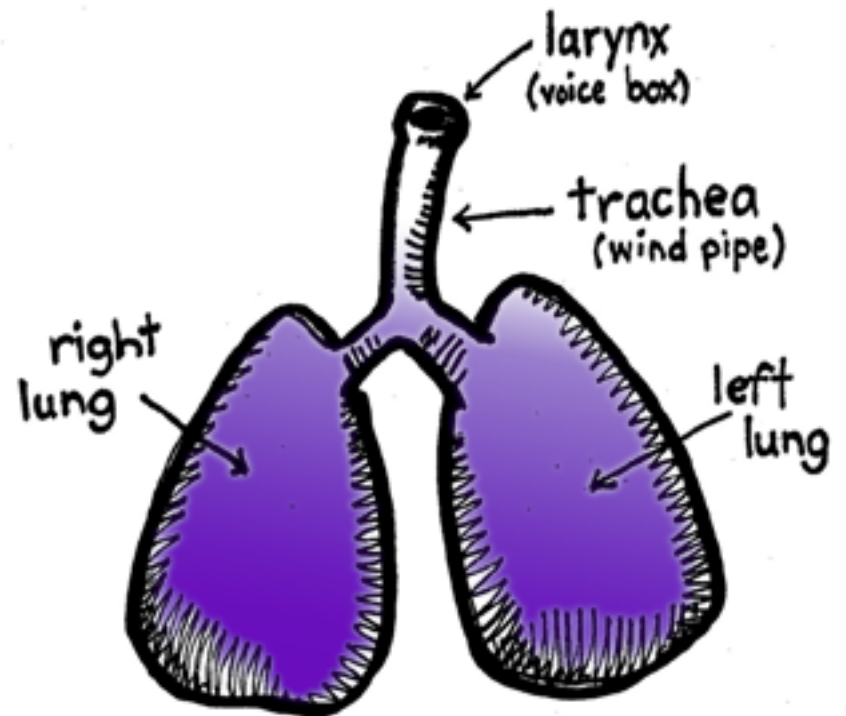


Beginners Guide



Thanks to our PROP clients and members for the quotes used in this booklet.

This Module discusses some of the issues you may be experiencing as a new ventilator user. We talk about how you and people close to you may be feeling. We talk about getting out and about in the community.

The Module also includes some information that will help ensure your safety and comfort. It concludes with useful tips from some of PROP's clients.

"Worry not about yesterday, you have no control over tomorrow, so live today to the fullest (within your limitations). The ventilator can become an invisible partner."

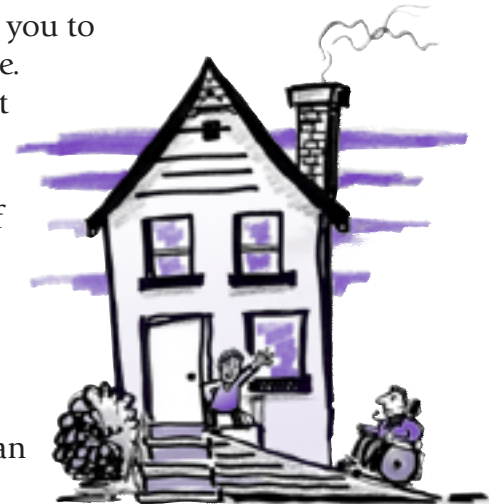
Adjusting to change

Ventilators are very portable and with the appropriate support you should be able to continue with your regular daily activities including working, shopping, visiting friends, and going to appointments etc. In fact, you may have found that since you started using a ventilator you have more energy than you did before and are more active in your community. You may be sleeping better and have additional stamina.

On the other hand, having a tracheostomy can result in feelings of sadness, shock, grief, anxiety, and disbelief. You may be finding it hard to adjust to being more dependent on others. All these feelings are to be expected. They are natural emotions that people encounter as they adjust to using a ventilator.

Another emotion people may have is loneliness: they may feel that no one really understands what they are experiencing. Everyone reacts and adjusts differently, but sharing how you feel with other ventilator users will help you to see that you are not alone.

PROP's Peer Support Group is a community of ventilator users who can help answer many of your questions and provide you with social support. Ventilator users have a unique first-hand perspective. An amusing "never again" anecdote, an innovative solution to a





technical problem, or just a chat over coffee can help you to overcome loneliness and feelings of isolation.

It will also help to share your feelings with your personal

support network of caregivers, family and friends. Sometimes people benefit from professional counselling; talk to your doctor or caregivers if this is something you are interested in pursuing.

It takes time to adjust. You may find it hard to believe now, but in time you will stop being conscious of your ventilator all the time. As PROP's Heather Morrison says about hers, "I don't think about it. I don't think about my refrigerator either." (*Inspiration* [video]).

Other People

Other people's reactions will vary. As you go out in the community, some people will appear not to notice your ventilator, others may look away; children may ask you or their parents blunt questions. Some ventilator users find it helpful to wear turtle necks or scarves to conceal their tracheostomy tube.

Again talk to other ventilator users about their experiences. Heather Morrison, for example, has a poodle called Nikki who accompanies her everywhere. Nikki has helped Heather to make friends and reach out to others in the community: "She bridges the gap between me and others, especially children. People see Nikki and come up and pet her. They only notice my ventilator afterwards and

by then they are at ease and don't feel intimidated by it." (*PROP News*)

Curiosity is a great motivator of human behaviour. People will look at you—try and understand and accept that this is quite natural. As one ventilator user says of this experience, "I am different, and it is natural that people should want to know, well what's this guy all about?" (Walt Lawrence, *Inspiration* [video]).

You may feel awkward at first, but it will get easier. Take things slowly and on your own time.

Your Personal Support Network

Your family members and friends also need time to adjust. For example, the extra support you require means your family will need to adapt to having additional caretakers in the home with 24-hour access. Younger children sometimes need reassurance about the ventilator and its safety. Like you, your personal support network of people close to you will experience a range of emotions.

Work on gently educating your friends and family about your ventilator. They may have questions and concerns that they want to talk to you about, but feel awkward raising. Try and encourage them to talk if you

"The big thing is don't lose hope, but if you do, remember that tomorrow is a new day. Just keep all doors open because you will be amazed who comes through them."

feel comfortable doing so. It is best for everyone to speak as openly and honestly as possible.

Of course your support network needs to have a good understanding of your needs. PROP provides respiratory education courses for primary caregivers, family and friends.

Getting Out and About



As we have said, with appropriate support you will be able to continue doing normal activities and participating in the community. You should also be

able to go on longer trips and travel further afield.

You may have been a wheelchair user before you began using a ventilator, so you know that before visiting a building for the first time it is a good idea to first check that it is fully accessible. As a ventilator user, the dimensions of your wheelchair may have changed. If so, you will need to recheck the accessibility of buildings you have previously visited.

With a bit of planning, you will be able to travel comfortably by car, airplane, train, boat, bus and use accessible transit. For safety reasons, you may prefer not to travel alone; however, as you become more experienced you may feel sufficiently comfortable to travel short distances unaccompanied. Travelling will become easier as you become more comfortable and more familiar with your needs. Again, it is a good idea to talk to ventilator users to learn from their experiences. They will be able to tell you what worked for them and what didn't.

If you are travelling a long distance, you will need to

take a travelling companion or attendant with you who has ventilator training. Attendants travel free or at half price on many modes of transport including planes and trains.

Check with your travel agent or directly with the carrier.

When you travel by air, train, boat, or bus, make sure that the carrier knows you are a ventilator user, and that they understand your needs and can accommodate them. Don't be shy about asking lots of questions: for example, does the carrier have any special policies regarding ventilator users that you need to know about?

You will of course need to take all your supplies with you. Consult PROP about what you need to take with you on your trip. Finally, it is a good idea to obtain a letter from your doctor that indicates you are able to travel and describes your health care needs.

Summing up

We have focused on some of the adjustments that you will be making as a new ventilator user and offered some ideas that may help you. We have talked about sharing your feelings with the people close to you and with other ventilator users. We have pointed out that adjustment takes time.

Finally, we've stressed that as a ventilator user, you will be able to lead an active life. The final word goes to Johanna Johnson:

"As you get into the rhythm of your life you do forget you're on a vent."

Your Safety and Comfort

The following is a review of some of the supplies and procedures required to help ensure your safety and comfort. Remember to contact PROP if you have any questions or concerns about your respiratory equipment, and if you don't yet have one ask us for our Ventilator Function Test Checklist.

Ventilators

BACK-UP SUPPLIES

Always have the following available in case of an emergency:

- Bacterial filters (front)
- Bagging unit
- Circuits, including exhalation manifold
- Flex hoses
- Gloves
- Intake filters (back)
- Spare exhalation valve (balloon)
- Spare tracheostomy tube
- Suction catheters
- Tracheostomy adapters
- Water traps



Circuit changes and cleaning

Replace your entire circuit (except the exhalation manifold) every 12 months. We recommend that you clean your circuit every week following this procedure:

- Disassemble the circuit
- Wash it in warm soapy water using mild soap
- Rinse
- Soak it in a solution of 1 part vinegar to 3 parts water for 30 minutes
- Rinse
- Hang to dry

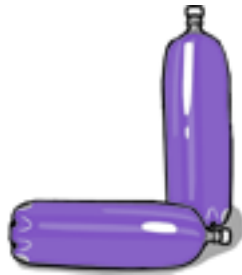
Humidifiers

Humidifiers increase the vapour content of the air you inhale. Here are some recommendations on using them:

- Always clean and disinfect according to the manufacturer's directions
- Never leave your bedside humidifier turned on when you are not using it
- Clean and replace the water everyday using only distilled or de-mineralized water. This will extend the life of your humidifier chamber.
- If sterile water is required, the distilled or de-mineralized water must be boiled and left to cool

Use Distilled Water

If your humidifier contains scale or crusty deposits, or is covered by a white dust, then you are probably using water that contains minerals. It is important to use the right type of water, because minerals can result in the growth of micro-organisms, and will also shorten your humidifier's life.



Tap water always contains minerals. Only use it if you have no de-mineralized water available. Use bottled water that is labeled "distilled." This can be purchased at your local drugstore. **Do not** use bottled waters that are labeled "spring," "artesian" or "mineral" because they may contain minerals. Water filtering systems like those you place on your refrigerator remove some odours and chlorine, but are not effective in removing the minerals that cause scaling and deposits.

Batteries (for LPG and LP10 Users)

Checking the internal battery's charge level: Unplug your ventilator from its wall socket or wheelchair battery connector and switch it from **standby** to **assist/control mode**. Press and hold the battery test button and watch the patient pressure meter needle. The numbered scale indicates the percentage of battery charge level. For example, if the needle points to 100, this means it is 100% full. Always charge the internal battery if it is less than 50% full.

Testing the power level of your internal battery: You should test your internal battery once a month. To test, make sure your ventilator has been fully charged and you

are not using it. Disconnect your ventilator from the wall socket or wheelchair battery and let it run until the low power alarm comes on. Note the start and stop time of the test. If the test result is under 45 minutes call PROP. The battery probably needs replacing. Make sure you recharge the battery after testing so it is ready to use.

Charging: Disconnect your ventilator from the wheelchair battery and plug it into a wall outlet. Charge your battery **daily**. Charging your wheelchair when your ventilator is connected **will not** fully charge your ventilator's internal battery.

Liquids and Your ventilator

- Keep all liquids away from your ventilator
- Rain and snow can damage your ventilator if it is not properly covered. Contact PROP for advice on how to cover your ventilator to protect it in wet weather.
- It is essential to call PROP anytime liquid is spilled on your unit. Do so even if the unit appears to be functioning normally.

"When I first got injured, I wouldn't have believed there would be any value living with a spinal cord injury—living ventilator dependent. Now, I wouldn't trade my life for anybody's."

PROP's Client Tips



- Although life has been a challenge, I try to face each day with optimism. (Ted Alliston)
- Check your respiratory supplies on a monthly basis. Keep enough stock on hand so that you only need to order supplies a few times a year. This way there is no panic when you run short or something is no longer available. (Jeanette Andersen)
- Never, ever go anywhere without your Ambu bag. (Alan Hurst)
- I have a two-wheeled cart (the kind used by seniors for shopping) that a friend bought in a thrift store for \$3.00. It's very handy for transporting a back-up ventilator to and from a vehicle and it makes it so much easier for an attendant. (Jeanette Andersen)
- Always take an emergency kit and a portable suction machine with you. Check both regularly to make sure they work. Carry extra suction catheters in your backpack. (Jeanette Andersen, Johanna Johnson, and Heather Morrison)
- Take a back-up vent if possible, particularly if you are going on a long trip. This will increase your comfort and your attendant's. (Jeanette Andersen, Johanna Johnson, and Heather Morrison)
- Carry a cell phone. If you travel on your own you may need a voice-activated phone. Check that your phone is well charged before you go out. If you use a pre-paid system make sure you have time left on your account. (Jeanette Andersen, Johanna Johnson, and Heather Morrison)

- When I travel I always pack an extension cord with a couple of plugs. You would be amazed where hotel rooms have their plugs in the wall: sometimes your ventilator plug will not reach and many hotels do not have extension cords available for their guests. (Zosia Ettenberg)
- Write down all your vent settings and store them in a safe place. Inevitably you'll get your vent back (from repair) and the settings will have been changed. (Johanna Johnson)
- Be organized and informed. Know your equipment and how to troubleshoot for problems. Know your vent settings. (Jeanette Andersen)

"I was always afraid to face the challenges given to me, but once I opened up and trusted myself I became a stronger person—in charge of my own destiny."

Thank you to the authors of "An Introduction to Mechanical Ventilation," Bloorview MacMillan Centre, Erinoak Serving Young People with Disabilities, Sunnybrook Health Science Centre, The Muscular Dystrophy Association of Canada and West Park Hospital.