

Exploring the Option of a Trach

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Planning for changes in your breathing condition takes courage. It is natural to avoid thinking about a possible breathing crisis. Yet, making informed decisions about your treatment options before a health crisis occurs has several benefits. First, it gives you the chance to consider factors that are important to you, such as spiritual and/or religious beliefs, personal values, and practical needs. As a result, you can make a decision that brings you peace of mind. Then, it also helps to reduce the problems and distress that loved ones may experience, especially if your wishes are unknown. Finally, it helps to ensure that your wishes are respected. Otherwise, if you are unable to communicate your wishes and do not have written instructions, your health advocate, surrogate, or closest family member will decide whether to employ or decline emergency interventions. This can make a difference between life and death!

Non-invasive ventilation (NIV) is the most appropriate form of ventilation for most people with neuromuscular respiratory conditions. However, when some vent users have needed stronger ventilation to breathe effectively, they have obtained a tracheostomy (trach). The main benefit of a trach is that it forces air directly into the lungs, providing greater respiratory assistance. This article offers a process for deciding whether you want, or do not want -- and can afford -- to use a trach in either of two scenarios: for the short-term, in order to save your life during an emergency and until you later recover; or for the long-term, if non-invasive ventilation no longer meets your needs.

In addition to helping you make a decision about using a trach, this article can help you talk with your pulmonologist about your options and decisions when:

- You encounter a life-or-death crisis and are unconscious.
- You cannot breathe and function adequately using non-invasive ventilation (NIV).
- You need to use NIV all day or for the majority of the day, and are interested in whether a trach's airway hole would enable you to function without a ventilator for extended periods.
- You are prone to pneumonia and respiratory infections **and** continue to have difficulty clearing mucous secretions even with techniques such as a Cough Assist machine or an Ambu bag.
- You need to be intubated periodically.
- You have irresolvable problems with your sinuses, digestive system, skin, or teeth from using a nasal or full face mask, mouthpiece, or nasal pillows.

If you decide you want to be trached in any of these situations, it is essential that you tell your physicians and write down that you are aware of the challenges of living with a trach, but consider it vital to your desire to stay alive.

“I would definitely prefer to use NIV if it enabled me to breathe and function adequately. After using NIV for more than 22 years, I experienced frequent breathing problems and spent increasing amounts of time during the day on my volume ventilator. Then, after an emergency surgery and respiratory failure, I could no longer breathe on my own when I was off the ventilator. Receiving a trach saved my life!

With the trach, I am able to function off my ventilator during the day for extended periods. The airway hole allows me to inhale and exhale room air, enabling me to breathe easily. Since I still am unable to breathe through only my nose, I would need to be connected to NIV all day if I didn't have a trach. Even when I used NIV with custom-made masks, I had difficulties with air leaks. I also had bloating problems from air that traveled to my stomach. I value the mobility and freedom that my trach affords me. I am grateful that it keeps me alive and able to experience what gives meaning, satisfaction, and serenity to my life.” **Linda Bieniek, Polio Survivor and Vent User: NIV 22 yrs, Trach 3 yrs**

Learning about the Pros and Cons of a Trach

Obtaining a trach requires a surgical procedure in which a physician creates an airway hole into a person's neck and places a tracheostomy tube into the trachea. When the trach tube is connected to a ventilator via tubing, the ventilator delivers air directly into the lungs, providing strong support to the breathing muscles. A trach also makes it easier to suction mucous secretions directly from the lungs.

Practical problems of living with a trach depend on where you live; the services and resources available to you from government programmes, social service agencies, and health insurance benefits; and your financial assets. At this time, many countries do not have health policies that pay for the ongoing expenses related to living with a trach. Unless you are physically able to do your own trach care and suctioning, having a trach normally requires a great deal of personal assistance that can be costly. Some areas provide in-home personal assistance, but often it is limited and may be inadequate. Most individuals do not have enough family members and friends who can volunteer to provide the amount of assistance needed. If you face this dilemma, the costs for assistance may prevent you from affording to live with a trach. This is especially true unless you have access to significant financial resources or enough reliable volunteers to assist you. Most vent users want to live in the community, yet most areas lack accessible, affordable housing options. A few countries provide long-term living facilities; other areas have only a few government-funded facilities that accept only a limited number of trach users. Often, facilities may be located a distance from your family and friends. Questions in this article can help you identify your options and the additional resources you would need to afford to live safely with a trach.

“The cost of care and caregiver legislation and conditions become ‘monumentally’ more difficult if you have a trach (especially 24/7) and are trying to live in the community...the ‘RN only’ restrictions in many areas create a huge liability, unless you can take care of your trach yourself- especially the suctioning.”

Audrey King, Polio Survivor and Non-Invasive Ventilator User-- Used a Trach for 2 years

*“When I got home from the hospital I did my own trach care....I had help when doing a complete trach change, once a month at first and now once every other month.I need to be suctioned, on average, about once a day. Sometimes I go a week between suctioning and sometimes I’ll be suctioned two or three times in one day.” **Richard Daggett, Polio Survivor and Ventilator User with a Trach since 1984***

Emotional, psychological, and spiritual issues are critical to consider when deciding whether to use

a trach. These issues often affect your reactions to change, loss, pain, suffering, and distress. For example, if spirituality (spiritual values or religious beliefs) is important to you, it may help you decide whether living with a trach matches your values and beliefs about life. On the other hand, if you have a short temper when you feel out of control, your negative reactions to difficulties related to a trach may result in your friends wanting to spend less time with you. For this reason, taking time to reflect on the emotional difficulties that you may encounter will help you identify the support and problem-solving strategies you would need to adapt to living with a trach. Potential emotional challenges include:

- **Feelings of loss:** of control, autonomy, independence, mobility, identity, quality of life, communication, and participation in external events and activities.
- **Fears of:** dependencies, physical vulnerability, feeling trapped, abandonment by loved ones and friends, feeling like a burden, isolation, institutionalization, and being alone.
- **Emotional reactions:** grief, anger, spiritual emptiness, shame, disappointment, loneliness.
- **Physical, cognitive, and emotional symptoms** of anxiety, depression, and/or distress.

Such losses, reactions, and experiences may affect many parts of your life including your relationships, employment, income, identity, living situation, spirituality, intimate experiences, roles in the family, and sexual activities. You can ease the adjustments of living with a trach by learning about factors that affect your emotional health and how you can strengthen your skills to resolve potential difficulties.

If you decide to use a trach, changes in your life will most likely also impact loved ones and supportive friends. For this reason, it is important to discuss your needs openly and honestly with these individuals before getting a trach. Likewise, find out what others think they will need from you to keep your relationships mutually supportive of each other. This discussion will enable you to agree to how to support and respect each other’s needs. Individuals who assist you must find ways to protect their personal needs. Otherwise, they can wear down physically and become distressed.

Lists at the end of the article identify sources of support for adjusting to and living with a trach. To learn how to strengthen your emotional health and reduce distress, ask your health provider or contact International Ventilator Users Network at info@ventusers.org or 001-314-574-0475 for a copy of “Ventilator User Guidelines for Emotional Health.” Obtain a copy of the “Treatment Approach Options Chart” from <http://www.post-polio.org/edu/pphnews/pph19-1p9.pdf>.

“When I first came home with a trach, I was distressed about difficulties: infections; greater needs for assistance; costs of home care; and loneliness when I was unable to talk until an ENT gave me the right-sized trach. Yet, I have NO REGRETS about getting a trach.” Linda Bieniek, Trach User since 2006

Benefits and Disadvantages of Using NIV or a Trach

Review the information below and note issues that will challenge you and/or potentially distress you.

Benefits of NIV With an Interface	Disadvantages of NIV & Interface	Benefits of a Trach	Disadvantages of a Trach
<ul style="list-style-type: none"> • Can save and extend your life by providing breathing assistance at night and/or during day • Presents less intense emotional, psychological and spiritual challenges • Enables you to obtain breathing assistance without creating a hole in your throat 	<ul style="list-style-type: none"> • You may face emotional, psychological, and spiritual challenges affecting your self-esteem, identity, work, income, relationships, activities, sexuality • May require continuous use of NIV for 24 hours or for extended periods during the day, limiting your abilities to see, eat and communicate easily 	<ul style="list-style-type: none"> • Can save your life if you cannot breathe using NIV; experience respiratory failure; have dangerous blood gas levels and minimal lung vital capacity • May enable you to breathe through your airway hole while off the vent for periods during the day, reducing your need to be on your vent continuously 	<ul style="list-style-type: none"> • You will face emotional adjustments and challenges that may distress you. See section on “Emotional, Psychological, Spiritual Issues” above • Requires an invasive procedure to create an airway hole in your trachea
<ul style="list-style-type: none"> • Is increasingly a subject of interest in medical schools and healthcare programmes • Has gained recognition as a cost-effective option for individuals needing breathing assistance 	<ul style="list-style-type: none"> • You may lack access to: <ul style="list-style-type: none"> ➤ Knowledgeable healthcare providers ➤ Home health services ➤ Effective ventilators, machines ➤ Mask and mouthpiece options 	<ul style="list-style-type: none"> • Is generally understood by emergency medical professionals 	<ul style="list-style-type: none"> • You may lack access to: <ul style="list-style-type: none"> ➤ Knowledgeable healthcare providers ➤ Home health services needed for living with a trach
	<ul style="list-style-type: none"> • May leak air and limit the air that reaches your lungs via a mask, mouthpiece, or nasal pillows 	<ul style="list-style-type: none"> • Provides most direct delivery of air into your lungs 	

<ul style="list-style-type: none"> • Reduces risk of infections by providing ventilation without an airway hole exposed to external bacteria • You may use secretion management techniques to help release mucous 	<ul style="list-style-type: none"> • Increases difficulties removing secretions if you lack the ability to cough • May cause sinus congestion from using a mask or dryness from using nasal pillows 	<ul style="list-style-type: none"> • Helps remove secretions: <ul style="list-style-type: none"> ➤ Can suction mucous through airway hole ➤ Provides direct access to lungs via Cough Assist machine or Ambu bag technique 	<ul style="list-style-type: none"> • Increases risks of infections from airway hole's exposure to bacteria and the external environment
	<ul style="list-style-type: none"> • May reduce your ability to see, talk, and/or eat easily if you use a nasal or full face mask during the day • May interfere with speaking and/or eating if you use a mouthpiece continuously during the day • You may experience difficulty finding an interface (mask, mouthpiece, nasal pillows) that fits comfortably and securely 	<ul style="list-style-type: none"> • Allows you to see and eat – essential functions of daily living 	<ul style="list-style-type: none"> • May require use of a speaking valve to talk • May need a different sized trach—usually smaller--that will allow you to talk • May prevent your ability to talk. Need to consult specialists for different options. • You may need to find the brand and size of a trach that best suits your needs
<ul style="list-style-type: none"> • Involves no risk of internal bleeding • Results in less secretions 	<ul style="list-style-type: none"> • May cause problems: <ul style="list-style-type: none"> ➤ Bloating from air traveling into the stomach ➤ Distortion of teeth from long-term use of mask or mouthpiece ➤ Skin irritation from masks and/or straps ➤ Sinus dryness from nasal pillows 		<ul style="list-style-type: none"> • You may experience bleeding: <ul style="list-style-type: none"> ➤ From irritation of frequent suctioning ➤ From granulation tissue at trach opening and tracheal mucosa • Increases need to: <ul style="list-style-type: none"> ➤ Manage secretions ➤ Provide humidity ➤ Clean equipment
<ul style="list-style-type: none"> • Requires less need for assistance because there is less equipment to clean and fewer tasks to perform • Increases your freedom and control if you are able to use your arms and hands 	<ul style="list-style-type: none"> • Requires assistance if you are unable to use your arms and hands to set up and clean humidifier • May require additional equipment for humidity 	<ul style="list-style-type: none"> • You may perform your own suctioning and trach care if you are physically able • May train family, friends, volunteers and non-agency personal assistants to suction and perform trach care 	<ul style="list-style-type: none"> • Requires daily care for: <ul style="list-style-type: none"> ➤ Suctioning ➤ Cleaning trach site ➤ Maintaining equipment • May require a great amount of assistance if you cannot perform tasks independently
<ul style="list-style-type: none"> • Provides greater mobility if you need NIV during the night and for limited daytime hours or can easily attach the machine to your wheelchair or scooter, if needed 		<ul style="list-style-type: none"> • May mount ventilator equipment to wheelchair or scooter to increase mobility 	<ul style="list-style-type: none"> • Reduces ease of mobility and traveling because of all the equipment and supplies needed

<ul style="list-style-type: none"> • Increases ability to travel because it requires less equipment and supplies 			
<ul style="list-style-type: none"> • Increases options to live: <ul style="list-style-type: none"> ➤ Independently ➤ In the community ➤ In a long-term facility 			<ul style="list-style-type: none"> • May reduce options to live: <ul style="list-style-type: none"> ➤ Independently ➤ In the community ➤ In a long-term facility based on its availability in your country/area
<ul style="list-style-type: none"> • Reduces costs for assistance due to fewer tasks 	<ul style="list-style-type: none"> • Requires out-of-pocket expenses depending on: <ul style="list-style-type: none"> ➤ Level of assistance needed ➤ Where you live and whether the area provides in-home care 	<ul style="list-style-type: none"> • Some countries cover costs for in-home assistance and/or care in a long-term facility 	<ul style="list-style-type: none"> • May require significant out-of-pocket expenses based on: <ul style="list-style-type: none"> ➤ Your area's provisions for in-home services ➤ Your physical abilities ➤ Amount of assistance from volunteers ➤ Cost of non-agency assistants ➤ Legal requirements for hiring agency assistance

By planning ahead, you can explore resources for potential assistance and support. If you are able to live in the community, family members, friends, volunteers, and personal care assistants whom you hire, can be trained to perform your trach care needs. If you hire assistants from a home health agency, legal restrictions may allow only nurses and respiratory therapists to provide trach care and ventilator assistance. Since hourly fees for these professionals are costly, most vent users hire non-agency assistants who charge more reasonable fees. However, if you only can afford to pay only low wages, you may find it difficult to hire competent, trustworthy, reliable assistants. In addition, if a non-agency assistant cannot work, you will need back-ups who are available and willing to help you on a short notice.

You also can seek volunteers from local non-profit and disability organizations, religious or spiritual communities, and educational programmes for healthcare providers (such as those for pre-medical students, respiratory therapists, nurses) even if these groups do not have formal volunteer programmes. Before contacting the directors of these programs, find out their names (such as of the programme director or volunteer manager). You may need to make several calls and send emails or letters until you gain a positive response to your request. When an organization provides or refers volunteers, you most likely will be asked to sign a legal waiver releasing the organization and its volunteers of any legal responsibility for problems with your care. You are responsible for ensuring that volunteers are properly trained and managed to meet your needs when they assist you.

Healthcare providers, family, and friends may vary in their views of living with a trach. For example, Dr. John Bach believes that “*Nobody... should have a tracheostomy tube for respiratory management – ever.*” Dr. Bach is extremely knowledgeable about human physiology and prescribes using NIV 24 hours each day for vent users with very low vital capacities. While using NIV throughout the day works for some individuals, it may not suit the lifestyles and preferences of others. Richard Daggett, a Post-Polio Support Group leader, wrote to Dr. Bach about this viewpoint:

“Polio survivors differ and need medical care based on each individual’s needs and not on a preconceived idea of what is best for “everyone.”...I have had a trach since 1984. It was my decision. I breathe easier and manage colds much better. I asked for the trach. Certainly a trach is not for everyone. Non-invasive respiratory assistance should be tried first. I firmly believe, however, a trach is a viable option for some.”

Some people believe that living with a trach results in poor quality of life. However, a Toronto study of vent users found that participants reported satisfaction with their overall quality of life. Also, the medical journal **CHEST** published an article on the “Quality-of-Life Evaluation of Patients with Neuromuscular and Skeletal Diseases Treated with Noninvasive and Invasive Home Mechanical Ventilation.” The article states that trach users with the following conditions reported better health than users of NIV:

“Patients receiving home mechanical ventilation reported a good perceived health, despite severe physical limitations. The patients with post-polio dysfunction and the patients with scoliosis treated with tracheostomy perceived the best health, compared with NIV for this diagnosis.”

CHEST 2002; 122; 1695-1700

Other individuals view the amount of assistance that trach users need as a burden to families and society. What is important is that **you decide** whether you want to live and can adjust to a trach. Then you will need to find out if you have a suitable, affordable place to live and can obtain and afford the amount of assistance, supplies, and equipment you will need to live safely and comfortably with a trach.

Deciding Whether to Use a Trach

Since some of the following issues are complex and may trigger anxiety, you may want to work through this process with the support of a wise friend, mentor, counselor, therapist, or spiritual director. Make sure that the person understands and values disability issues in the context of “independent living.” For information about this philosophy, check out <http://www.post-polio.org/adv/index.html>.

Gather Information and Insights

The process below can help you decide if you can adapt to living with a trach and if you can afford a place to live and the level of assistance and resources you will need to live safely and comfortably with it.

1. Learn about more about using a tracheostomy from:

- a. **International Ventilators Users Network (IVUN).** www.ventusers.org for information, articles, and referrals to other vent users. See *Home Ventilator Guide* and *Resource Directory for Ventilator-Assisted Living*. Call 001-314.534.0476 or access at <http://www.ventusers.org/net/VentDIR.pdf>.
- b. West Park Health Centre's e-learning modules: www.westpark.org
www.ltvcoe.com/training_oelib_home.html.
- c. Ottawa Rehabilitation Institute's e-learning modules: www.irrd.ca/education.
- d. University of Toronto study on "Ventilator Users' Perspectives on the Important Elements of Health-Related Quality of Life." <http://www.post-polio.org/res/QofLFINALREPORT-Sept2002.pdf>
- e. Feedback from other trach users. Join vent users' ListServes in the *Resource Directory for Ventilator Assisted Living* at <http://www.ventusers.org/net/VentDIR.pdf> Consider opinions of others objectively since personal attitudes differ for a variety of reasons.
- f. A CHEST video of Audrey King describing her challenges of living with a trach for two years while recovering from an illness. Contact mlederer@chestnet.org for a copy.

2. Obtain information and opinions to determine your options and available resources from:

- a. Your pulmonologist: the pros and cons of a trach given your condition and circumstances.
- b. Other pulmonologists specializing in home mechanical ventilation. Obtain referrals from IVUN info@ventusers.org or 001-314-534-0475 or from the *Resource Directory for Ventilator-Assisted Living* that you can access at <http://www.ventusers.org/net/vdirhm.html>
- c. Home health providers that service ventilator equipment and individuals with trachs in your area.
- d. Government programmes and/or your health insurance provider to determine the services and benefits for which you qualify and the procedures for obtaining them.
- e. Social service agencies for available services and how to apply for and obtain them.
- f. Family, relatives, friends, and others to learn how much time and assistance they can provide.

3. Think about what you have learned. Do you want to explore the possibilities of using a trach further? If you do, the questions in the grid below can help you determine your needs.

Assess Your Resources and Needs

As you ask yourself these questions, write down your responses. They will help you identify your ability to adapt to a trach, available resources, and additional resources you would need. These include healthcare resources, personal assistance, emotional support, and the ability to afford what you need.

Healthcare Resources:

- Do you have access to knowledgeable, responsive healthcare professionals: pulmonologist, home health providers, and an accessible hospital equipped to handle ventilators and individuals with tracheostomies?

Emotional Resilience:

- Do you consider your life worth living? What makes life worthwhile for you?
- Do you have a purpose in life? How do you imagine you will fulfill your purpose while living with a trach?
- How creative and resourceful will you be in fulfilling your personal needs?
- What are healthy ways you will use to express your needs and feelings?
- How will you respond to distress? How will you support yourself emotionally?
- What access do you have to behavioural health professional(s) and resources for emotional assistance?
- Are your spiritual values and/or religious beliefs important to you? If yes, how will they affect your decision?
- What spiritual and religious resources are available to support you? What connections would you need?

Coordination of Care:

- Do you have a dedicated “Health Advocate/Surrogate” who understands your medical conditions, special needs, preferences, and would speak on your behalf with health professionals? Who could you ask?
- Is this person willing and able to oversee the coordination of your care?
- Who would be your reliable “Communication Coordinator” to inform your support network of your condition and needs and also relay their suggestions and messages back to you?

Daily Assistance:

- Are you capable of doing your own trach care and suctioning?
- How much additional assistance, from what you already have, will you need if you have a trach?
- Will you need help for 24 hours of each day? If yes, do you know who will provide that assistance?
- Do you have enough of reliable, trustworthy assistants to provide daily trach care, coordinate services and appointments, transport you to them, respond to emergency needs, and enable you to function effectively?
- Can you hire and manage personal assistants or do you have reliable, skilled people who will do that for you?

Financial Costs:

- What costs will health insurance, government programmes, and/or social services pay for?
- What do you estimate your out-of-pocket costs will total after coverage from these sources?
- Can you afford to pay for the unreimbursed costs for personal assistance, supplies, and equipment?
- Do you have potential sources of income that you can use to cover these expenses?
- Will you be able to afford to continue living in your current residence or will you need to move to more affordable housing or a long-term residence that accepts and assists vent users with trachs?

Living Arrangement:

- Do you have a suitable place to live that will accommodate your additional needs with a trach?
- Are you physically strong enough to live alone with a medical alarm system that you wear and can operate?
- Do you have room for the additional equipment, supplies, and personal assistants you will need?
- Do you have access to government housing or long-term care facilities that will accept vent users with trachs? Are there openings? Do you qualify? Are you willing to live in this kind of residence? What are the costs?
- Do you have other options of living with family, relatives, or friends?

Support Network:

- Do you have reliable individuals to visit and assist you regularly? How many? How often?
- Do you have meaningful relationships you can depend on for emotional support and enjoyment?
- How could you stay connected with individuals and organizations? Through phone, computer, other means?
- Are you involved with organizations and/or spiritual or religious communities that could provide support or assistance or will help fulfill your spiritual or advocacy interests? Are you willing to pursue such options?

4. Decide:

- a. Does living with a trach match your beliefs about life and your values and goals?
- b. Do you think you can emotionally adjust to living with a trach?
- c. Will you have the resources and assistance you will need to live with a trach:
 - i. For the short-term, during a medical emergency and your recovery?
 - ii. For the long-term, if your breathing worsens and you need a trach to function?

5. Inform the appropriate individuals in writing of your decisions:

- a. Documented designates with Power of Attorney for your health care.
- b. Designated “health advocate(s) or surrogate(s)” to speak on your behalf
- c. Health care providers who treat you. Ask them to include your decisions in your medical records.
- d. Family and friends who may accompany you during an emergency or while in a hospital.

6. **Complete a copy of the “Take Charge, No Chances” forms or subscribe to a medical alert service which health providers can access.** Give copies of the TCNC forms to individuals who may accompany or assist; instruct them to bring the forms along when you travel or go to a hospital. They will inform providers with your ventilator settings and special needs. Access them at www.ventusers.org/vume/index or info@ventusers.org or by calling 001-314-574-0475.

Living with a Trach

When you decide to obtain a trach, review the lists below to understand the types of professional and personal assistance that are important to make the transition safely and effectively. If you are unable to arrange for the assistance you will need and want, ask loved ones or friends to coordinate them for you.

What Can Help: When You First Obtain and Adjust to a Trach

*“It is essential that every individual have a knowledgeable **health advocate** (surrogate) who understands their condition, past and recent experiences, personal preferences, and wishes. This advocate must be a person educated in the clinical need.....They should be kept abreast of new developments and usually should accompany the person in person when they access the health system, health facilities, use any health resources.” **Allen Goldberg, MD, Honorary Board Member of International Ventilator Users Network***

Work with Competent, Communicative Professionals

- Knowledgeable and compassionate pulmonologist specializing in neuromuscular respiratory conditions to determine and oversee your respiratory and ventilator needs
- ENT specialist to select the appropriate type of tracheostomy for your anatomy and respiratory condition, and then to surgically insert the tracheostomy into the trachea in your neck
- Health professionals to educate you about where you will stay in the healthcare facility, the process of getting a trach, suctioning, and trach care, as well as your pain management options
- Respiratory and speech therapists to help you adjust to breathing, swallowing, eating, speaking
- Physical and occupational therapists to help you regain your strength and resume daily activities
- Case Manager/Coordinator often oversee authorizations for services, communications about service delivery, and discharge planning in a hospital or healthcare facility
- Patient Relations Representative/Ombudsperson often may be available to resolve problems and ensure satisfaction with the quality of care you receive while in that healthcare facility
- Psychotherapist/behavioural health professional to assist you in managing distress and in adjusting to the limitations and frustrations of having a trach. You may need to request.

Build Personal Support

- Tell healthcare professionals and loved ones of yourself desire and determination to live
- Decide on how you will communicate your needs, wishes, and feelings if you cannot talk
- Designate “Health Advocate(s)/Surrogate(s)” to watch over your care, learn about your conditions and needs, and speak on your behalf with health professionals and other staff
- Ask a person with good organizational skills to seek and schedule daily visitors who will assist you and obtain the staff’s assistance in the healthcare facility, as needed
- Assign a “Communication Coordinator” to update people who care about you and to convey messages back to you. These websites provide an efficient way to communicate with others: <http://www.caringbridge.org/> or <http://www.carepages.com/>

Seek Forms of Comfort, Relaxation, and Energy

- Spirituality, prayers, kindred souls who share your values, beliefs, and/or cultural traditions
- Nutritional food and treats including fresh fruits and vegetables and good protein
- Supportive Touch: hand and foot massages, healing touch, gentle acupressure, back rubs
- Music: relaxing, uplifting music; your favorite songs and instrumental pieces
- Symbols and items that can lift your spirits; supportive cards and letters from others

What Else Can Help: When You Live with a Trach

Arrange for the Physical Assistance You Will Need

- Select home health providers who are efficient, responsive, and knowledgeable to provide the appropriate ventilator, other respiratory and medical equipment, and trach supplies
- Hire personal care assistants and seek volunteers who are reliable, competent, and trustworthy
- Plan for emergencies: complete “*Take Charge, Not Chances*” forms or use a medical information system to provide your ventilator settings and key information to healthcare providers; obtain an in-home medical alert system; develop evacuation plans; contact fire personnel and energy companies that supply power for your machines.

Seek Personal Support to Make Your Life Easier and More Satisfying

- Cherish loving, meaningful relationships that contribute comfort, serenity, and joy to your life
- Communicate with other trach users to gain ideas for solving problems and fulfilling needs
- Arrange for frequent visitors to assist you, share mutual interests, and provide good humor

- Join and get involved in disability and disease-related groups to obtain information and resources and to advocate for issues that affect your health and well-being

Explore Additional Opportunities for Serenity, Energy, Enjoyment

- Meditation, mindfulness, breathing and relaxation exercises, sitting yoga or tai chi
- Living space that is healthy, uplifting, and accessible to your needs
- Emotional health resources: see <http://www.post-polio.org/edu/pphnews/pph19-1p9.pdf>
- Pleasure, comfort, laughter: family, children, pets, the Arts, books, games, celebrations
- Interests: spiritual, intellectual, artistic, recreational, professional or occupational, cultural
- Access to outdoors and an ability to view nature.
- Bodywork: ethical and safe massages, cranial sacral therapy, gentle osteopathic manipulation therapy and other forms of relaxation and pain management

Join International Ventilator Users Network (IVUN) to learn about living well with ventilator-assistance and about the latest equipment, advocacy efforts, research, and networking opportunities with other ventilator users and healthcare providers who generously share their expertise with IVUN members.



The image shows the IVUN logo on the left, which reads "IVUN International Ventilator Users Network" and "An affiliate of Post-Polio Health International (PHI)". To the right is a screenshot of the IVUN website, which includes a navigation menu, a "Welcome to IVUN" banner, and several articles or news items.



A dark teal rectangular box containing the text "Visit ventusers.org" and the phone number "314-534-0475". To the right of the text is a small thumbnail image of the IVUN website.

As a ventilator user for more than 25 years, Linda Bieniek advocates for the health and quality of life of ventilator users. From her personal experience, and her professional knowledge as a Certified Employee Assistance Professional, she shares strategies for deciding about using a trach and for strengthening emotional health. The opinions in this article are hers alone unless indicated otherwise.

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