

# When Are Trachs an Option?

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**Home Mechanical Ventilation (HMV) has saved the lives** of many polio survivors and individuals with other neuromuscular conditions. Its benefits far outweigh its inconveniences and the psychological adjustments of needing a machine to assist with breathing. These include 1) Improving quality of sleep, daytime functioning, and quality of life; 2) Increasing lung functioning, energy, muscle strength, longevity; and 3) Strengthening the immune system and reducing risks of respiratory illnesses.

We believe that non-invasive ventilation (NIV) is the most appropriate form of ventilation for most people with neuromuscular respiratory conditions. However, some vent users have opted to use a tracheostomy (trach). Deciding to use a trach is a complex issue. In the following pages we offer information and assessment tools to explore the option of using a trach when NIV ceases to provide enough of respiratory support to function effectively. While using a trach is not suitable and affordable for every vent user, we consider it a valid option when NIV no longer meets a person's needs. Each vent user needs to decide whether NIV or a trach suits his or her medical conditions and lifestyles best.

*"I would definitely prefer to use non-invasive ventilation (NIV) rather than a trach if NIV enabled me to breathe adequately and function effectively. However, after using NIV for over 22 years, I had increasing breathing problems during the day when I was off of my volume ventilator. Then, in 2006, after an emergency surgery and respiratory failure, I could no longer breathe off my ventilator. I agreed to receive a trach to save my life.*

*With the trach, I currently am able to function off the ventilator during the day for extended periods. The airway hole allows me to inhale and exhale room air that I need to breathe easily. Since I still am unable to breathe just through my nose, I would need to be connected to NIV all day if I didn't have a trach. Even then, I am not sure that NIV would adequately ventilate my lungs. When I used NIV, I had difficulties with air leaks and air traveling to my stomach, exacerbating my IBS condition. I used numerous interfaces, including custom made masks. Despite NIV's advantages, I prefer the mobility and freedom that a trach currently affords me. I hope I will grow strong enough to return to using NIV; but if not, I will continue to depend on a trach to keep me alive and able to experience what gives meaning, satisfaction, and joy to my life."* **Linda Bieniek, Polio Survivor & Ventilator User: NIV 22 yrs, Trach 3**

*"It is essential that every individual have a knowledgeable **health advocate** 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, PHI/IVUN Honorary Board Member**, served as the health advocate for Margaret Pfrommer, a polio survivor friend who was paralyzed from her neck down and used NIV until her final years when she transitioned to using a trach.

**Obstacles to Using Home Mechanical Ventilation (HMV) include:**

1. **Lack of access** to knowledgeable healthcare professionals: pulmonologists, respiratory therapists, Emergency Room and hospital staff, and home health providers as well as equipped medical and long-term care facilities. Often, these are problems in remote areas and in developing countries.
2. **Psychological factors:** such as losses of control, independence, mobility, quality of life, self-esteem; relationship, intimacy, sexuality, and role changes; fears of institutionalism, isolation; anxiety and PTSD triggers; depression, and dissociation.

# When Are Trachs an Option?

## Benefits and Disadvantages of Trachs and Non-Invasive Ventilation

Tracheostomy		Non-Invasive	
Benefits	Disadvantages	Benefits	Disadvantages
<ul style="list-style-type: none"> <li>Saves lives when person cannot breathe sufficiently on NIV &amp; has dangerous blood gas levels &amp; minimal vital capacity</li> </ul>	<ul style="list-style-type: none"> <li><b>Possible Psychological Factors:</b> see “Obstacles” section above</li> </ul>	<ul style="list-style-type: none"> <li>Lower out-of-pocket costs for assistance &amp; supplies, especially if able to use arms &amp; hands</li> </ul>	<ul style="list-style-type: none"> <li><b>Possible Psychological Factors:</b> see “Obstacles” section above</li> </ul>
<ul style="list-style-type: none"> <li>Provides more direct and stronger ventilation to the lungs</li> <li>Reduces problems with interface leaks</li> <li>Reduces gastrointestinal problems since air is not traveling into the stomach &amp; causing bloating</li> </ul>	<ul style="list-style-type: none"> <li>May increase out-of-pocket expenses <b>significantly</b> for assistance &amp; supplies.</li> <li>Legislation limits agency care to RN or RT professionals with costly hourly rates.</li> </ul>	<ul style="list-style-type: none"> <li>Provides greater mobility if only needed at nighttime &amp; limited daytime hours</li> </ul>	<ul style="list-style-type: none"> <li>Interface air leaks limit the volume of air into the lungs</li> <li>Finding an interface (mask, mouthpiece) that fits properly &amp; comfortably</li> </ul>
<ul style="list-style-type: none"> <li>Provides breathing through inner cannula while off the vent during daytime periods rather than needing to use non-invasive vent continuously</li> </ul>	<ul style="list-style-type: none"> <li>Increases daily care needs:               <ul style="list-style-type: none"> <li>➤ Personal assistance</li> <li>➤ Suctioning</li> <li>➤ Cleaning equipment</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Reduces risk of infections because there is no airway (hole) that is exposed</li> </ul>	<ul style="list-style-type: none"> <li>No alarms. Tubing may disconnect, especially during asleep.</li> </ul>
<ul style="list-style-type: none"> <li>Aids recovery of pneumonias:               <ul style="list-style-type: none"> <li>➤ Suctioning access to mucous</li> <li>➤ Direct pressure via Cough Assist</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>May require using a speaking valve to talk</li> <li>Rarely unable to talk</li> </ul>	<ul style="list-style-type: none"> <li>Less need for assistance if vent user is able to use his/her arms &amp; hands</li> </ul>	<ul style="list-style-type: none"> <li>May reduce ability to see, talk, or eat easily with nasal or full face mask interface</li> </ul>
<ul style="list-style-type: none"> <li>Alarms when equipment disconnects or pressure changes</li> <li>Internal &amp; external batteries may last 7-8 hrs</li> </ul>	<ul style="list-style-type: none"> <li>Need for:               <ul style="list-style-type: none"> <li>➤ Secretion management &amp; humidity</li> <li>➤ Extra equipment, supplies</li> <li>➤ Back-up generator</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Provides greater independence &amp; mobility, higher self-esteem</li> </ul>	<ul style="list-style-type: none"> <li>24/7 users may experience some difficulties speaking &amp; eating with mouthpiece interface</li> </ul>
<ul style="list-style-type: none"> <li>Vent users with arm &amp; hand muscles may perform their own trach care &amp; suctioning</li> </ul>	<ul style="list-style-type: none"> <li>Possible risks of:               <ul style="list-style-type: none"> <li>➤ Infections</li> <li>➤ Bleeding from irritations</li> <li>➤ Granulated tissue</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Smaller, lighter equipment increases ability to travel</li> </ul>	<ul style="list-style-type: none"> <li>No back-up battery for emergencies.</li> </ul>
<ul style="list-style-type: none"> <li>Family, friends, &amp; personal assistants can be trained to suction &amp; perform trach care</li> </ul>	<ul style="list-style-type: none"> <li>May reduce the ability to live independently at home</li> </ul>	<ul style="list-style-type: none"> <li></li> </ul>	<ul style="list-style-type: none"> <li>Need for back-up generator during emergencies</li> </ul>

# When Are Trachs an Option?

*“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 & 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 & Ventilator User with a Trach since 1984**

*“The difficulties I’ve encountered living with a trach have been: 1) infections and pneumonias; 2) costs for needing greater assistance; 3) increasing dependencies; and 4) loneliness when I was unable to talk until we found the right trach. Yet, I have NO REGRETS about getting a trach.”*  
**Linda Bieniek, Trach User since 2006**

<b>Factors To Consider Before an Emergency</b> The questions in this table can help you identify your needs, available resources, and whether you can afford to live with a trach, and where. Each topic is important and relates to the challenges of living with a trach.	YES	NO	COMMENTS RESOURCES NEEDED
<b>Healthcare Resources:</b> Do you have access to knowledgeable, responsive healthcare professionals including a pulmonologist, home health providers, and an accessible medical center/hospital equipped to handle your use of HMV and a tracheostomy?			
<b>Psychological Resilience:</b> Do you consider your life worth living? Do you have a purpose in life? Can you fulfill it living with a trach? Are you creative and resourceful in fulfilling your personal needs? Do you use healthy ways to express and channel your feelings? Do you have access to external professionals and resources for support?			
<b>Coordination of Care:</b> <b>Do you have an available, dedicated “Health Advocate” who understands your clinical conditions, needs, and preferences and will communicate with health professionals and oversee coordination of your care on your behalf?</b> Do you have a dedicated “Communication Coordinator” who will interact with your support network to provide you and them with information, suggestions, resources, greetings, and prayers?			
<b>Daily Assistance:</b> Are you capable of doing your own trach care and suctioning? How much additional assistance will you need, if you have a trach? Will you need 24/7 help? If so, who will provide it? Do you have enough reliable assistants (family, friends, volunteers) to provide daily trach care, assist in emergencies, coordinate appointments with health professionals, home health providers, and suppliers? Are you able to hire and manage personal assistants or do you have a reliable, skilled person whom you can depend on to do that?			
<b>Financial Costs:</b> What costs will your health care insurance, government assistance, and/or long-term care insurance pay for, if any? What will your out-of-pocket costs total after reimbursements from health			

# When Are Trachs an Option?

<p>insurance and other sources?          Can you afford the unreimbursed costs for personal assistance, supplies, and equipment? Or do you have other sources for financial support?          Will you be able to afford to continue living in your current arrangement or will you need to move to a more affordable housing option?</p>			
<p><b>Living Arrangement:</b>          Will you be able to physically manage living in your current home or facility? Alone or with others?          Do you have room for equipment and personal assistants you will need?          Can you adapt to living in government-funded housing or a nursing home if you cannot afford in-home care?          Do you live in an area that provides publicly-funded long-term facilities for vent users with a tracheostomy that are available?          Do you have any other options of where you can move or live?</p>			
<p><b>Support Network:</b>          Do you have a strong network of reliable individuals who will visit and assist you with various needs?          Do you have meaningful relationships that you can depend on for emotional support and enjoyment?          Do you stay connected with individuals and organizations by using the phone and computer? If not, how?          Are you associated with non-profit organizations that will provide services, assistance, transportation, or visitors?</p>			

*“After experiencing the downsides of receiving a trach in an emergency situation without any prior planning, I highly recommend that vent users consider the following issues to help in making a rational decision about whether to use a trach in the short or long-term.”* **Linda Bieniek, Trach User**

## Explore Your Options and Decide on Whether to Use a Trach

1. **Obtain information** about using a tracheostomy with HMV from:
  - a. International Ventilators Users Network (IVUN). [www.ventusers.org](http://www.ventusers.org) articles on NIV and trachs, *Resource Directory for Ventilator Assisted Living*, and *Home Ventilator Guide*.
  - b. West Park Health Centre’s e-learning modules: [www.westpark.org](http://www.westpark.org)  
[www.ltvcoe.com/training\\_oelib\\_home.html](http://www.ltvcoe.com/training_oelib_home.html).
  - c. Ottawa Rehabilitation Institute’s e-learning modules: [www.irrd.ca/education](http://www.irrd.ca/education).
  - d. LISTSERVS’ participants. See list in the *Resource Directory for Ventilator Assisted Living* on [www.ventusers.org](http://www.ventusers.org). Consider comments from individuals objectively since their attitudes differ for a variety of reasons.
2. **Consult resources** to gain perspectives and determine your sources of support—healthcare, financial and personal:
  - a. Ventilator users, preferably who have used both non-invasive and invasive ventilation:
    - i. Obtain referrals from International Ventilator Users Network (IVUN): 314.534.0476. [director@ventusers.org](mailto:director@ventusers.org).
    - ii. Watch CHEST video of Audrey King describing her adjustments and challenging of living with a trach. Contact [mlederer@chestnet.org](mailto:mlederer@chestnet.org) for a copy.
  - b. Your pulmonologist to gain insights about the pros and cons given your conditions.
  - c. Other pulmonologists who specialize in HMV. Obtain names from [www.ventusers.org](http://www.ventusers.org): *Resource Directory for Ventilator-Assisted Living* or from IVUN at 314.534.0475.
  - d. Insurance carriers about your policy’s eligibility and reimbursement provisions.
  - e. Government and social service agencies to learn if you qualify for any services.

# When Are Trachs an Option?

- f. Your support network to find out the time and assistance they can commit to provide.
3. **Assess facts and opinions** you have collected along with the factors from the sections above:
  - a. “*Invasive and Non-Invasive HMV: The Benefits and Disadvantages*”
  - b. Your answers to questions asked in “*Factors To Consider Before an Emergency*”
4. **Decide** if you are willing and able to afford to live with a trach:
  - a. For the short-term, in case of a medical emergency and during your recovery?
  - b. For the long-term, if your breathing worsens or a situation listed on page 5 applies.
5. **Inform individuals in writing** of your decisions to accept or decline use of a tracheostomy:
  - a. Designated Powers of Attorney for health care. Include instructions in your Living Will.
  - b. The person(s) who will serve as your “health advocate(s).”
  - c. The person who will serve as your “communication coordinator.”
  - d. Your health care providers and family/friends who may accompany you in emergencies.
  - e. Professionals who can authorize submission of your decisions into a hospital/medical center’s electronic records.
6. **Complete** a copy of the “*Take Charge, No Chances*” forms and give a copy to key individuals. Include your ventilator settings and emergency wishes. [www.ventusers.org/vume/index](http://www.ventusers.org/vume/index).

**In Response to Dr. John Bach’s Assertion** that “*Nobody with polio should have a tracheostomy tube for respiratory management – ever.*” Many of us know of, and admire Dr. Bach’s understanding of physiology and work with HMV. While we have great respect for him and his dedication to his patients, we disagree with his assertion. Using NIV 24/7, as he does with individuals who have very low vital capacities, may not suit the lifestyles and preferences of all vent users. Richard Daggett, a Post-Polio Support Group Leader, responded to Dr. Bach’s claims. A few of his comments are stated below:

*“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.’ ...Dr. Bach contends that ‘trach tubes are foreign bodies. They contain very bad bacteria that go into the lungs.’ Yet instruments such as pacemakers and coronary stents are also ‘foreign bodies’ that save lives and enable individuals to live actively.*

*I have had a trach since 1984. It was my decision. I breathe easier and manage colds much better. No doctor told me, ‘You need a hole in your neck.’ 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.”*  
**Richard Daggett, Trach User since 1984**

A **CHEST** article entitled, “Quality-of-Life Evaluation of Patients with Neuromuscular and Skeletal Diseases Treated With Noninvasive and Invasive Home Mechanical Ventilation” concluded:

*“Patients receiving HMV 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**

**Before an emergency occurs, consider whether you want and can afford to use a trach when:**

- You are faced with a life or death crisis.
- You can’t breathe and function well enough using non-invasive ventilation (NIV).
- You need to be intubated periodically.
- You need to use NIV all day or the majority of the day and a trach’s airway would enable you to be more mobile and function without your ventilator for periods during the day.
- You encounter irresolvable problems with interfaces (e.g., gastrointestinal, skin, loosening of teeth).
- You prefer a trach’s advantages (e.g., secretion management) for your lifestyle.

# When Are Trachs an Option?

## Trach? Or Not?

Brenda Butka, M.D.  
Vanderbilt University School of Medicine

Why breathe?

“In with the good, out with the bad”

Pull in oxygen: fuel

Push out carbon dioxide: waste product

Breathing: The System

- Lungs: transmit oxygen/carbon dioxide
- Muscles: bellows to push/pull
- Airways: gas transit
- Brain: controller

Muscle weakness

- Lungs usually ok
- Not enough ventilation
- Poor cough

Consider

- Secretion management
- Ventilatory support

Secretion management = Cough

- Deep breath
- Strong exhalation
- Close glottis

Deep breath = volume

- Problem if VC less than 50%
- Supplement by
  - IPPB
  - Stacked ambu
  - Cough assist
  - Breath stacking

# When Are Trachs an Option?

## Exhalation

- Peak flow < 5 LPS
- Supplement
  - Manual assist cough
  - Cough Assist

## Close Glottis for Cough

- Vocal cord problems hard to fix
- Tracheostomy
  - Cap
  - Passy-Muir valve

## Secretion Management

- Cough Assist
- Suction
- Vibrating vest
- Flutter valve
- IPV

## Consider

- Secretion management
- Ventilatory support

## Ventilator support

- Invasive
- Noninvasive

## Tracheostomy: WHY?

- Bulbar involvement
- Decreased compliance: “stiff” lungs
- Secretions
- Airway obstruction
- Failure of NIV

## Tracheostomy Ventilation

- More secure
- Vents have batteries, alarms
- Usually can eat/talk
- Not necessarily 24/7
- Better interface for secretion management

# When Are Trachs an Option?

- Caregiver stress/fatigue
- May not have long-term care options on vent

Ventilator support

- Invasive
- Noninvasive

Noninvasive

- Usually Bipap with backup rate
- Can use volume ventilator
- Negative pressure: cuirass or “lung”
- Belt
- Rocking bed

Noninvasive interfaces

- Fullface mask
- Nasal
- Oral
- Mouthpiece

Noninvasive

- Can be 24/7
- Speech/eating unimpaired
- Airway not as secure
- Doesn't work if lungs are stiff
- Secretion management more difficult

## Explanations and Demonstrations of Equipment

Kristy McClellan, RRT, Vanderbilt Stallworth Rehabilitation Hospital

- a. Types of Trachs
- b. Types of Ventilation used with trachs (Bi-Pap, volume)
- c. Types of Suctioning
- d. Passy Muir Valve
- e. Cough Assist Machine
- f. Respiratory Therapist's role in managing ventilation and use of a trach