

Emotional, Psychological, and Spiritual Challenges

Whenever changes in our health results in losses, it's normal to experience emotions that are part of the grief process: shock, sadness, anger, and depression. For example, losses of control, mobility, or identity can trigger sadness, anger, loneliness. These reactions may impair our ability to function (e.g., if sleeping excessively), concentrate and think clearly, and/or maintain healthy relationships (e.g., if short-tempered, isolating)—symptoms of anxiety and/or depression.

One way to reduce such symptoms is to face our feelings with curiosity and a compassionate commitment to our well-being. These attributes will empower us to understand the reasons for our feelings, and then, to find useful, healthy ways to respond to the needs they express. The alternative of burying anger, sadness or loneliness increases our risks of developing symptoms of anxiety and depression.

My experiences related to getting a trach were emotionally very painful for me and my family and good friends. I obtained a trach to save my life after an unrelated surgery followed by respiratory failure. Going home physically weak and needing 24 hour care after living alone with NIV for over 20 years, presented many emotional, psychological, and spiritual challenges. A great deal of the distress that I and others experienced could have been avoided had I prepared for the possibility of needing a trach in advance; informed others of my willingness to get a trach; and carried critical information about my physicians and vent settings with me when I traveled (I was out-of-state traveling alone when my crisis occurred.).

As I confronted unexpected changes, I did not take time to grieve my losses. Initially, I focused on managing the distress of everyday frustrations (e.g., with caregivers, healthcare needs, family difficulties). In time, I faced my losses of independence, mobility, ability to communicate with ease, and identity; and came to a place of acceptance. Among the many lessons I learned from living with a trach, is recognizing the usefulness of taking time to become aware of the emotional, psychological, and spiritual effects of my experiences. This was useful because it gave me the ability to understand how my reactions related to unmet needs--what I needed at that time; to identify how to best to respond to these needs; and to make the necessary adjustments for living a good life.

After three years of living with a trach, I wrote the article “Exploring the Option of a Trach” to encourage other vent users to decide about using a trach, before the need arises; and if they agreed to this option, to plan for the support they may need to live a good life with a trach. In the following charts, I've identified individuals and resources that may help ease their own transitions and lives using a trach.

It Takes a Team

Depending on your level of need while using NIV or a trach, some or all of the people identified in the charts below may play a role in contributing to your health and your ability to live a good life: **The Specialists and Other Really Important People**. You can use the column on the right to jot down any actions you may want to take.

Part One: The Specialists

Person/ Organization	Their Roles	Action Needed
Myself!	Determined to live! Aware of my needs and feelings. Able to communicate in some form. Know about my health conditions.	
International Ventilator Users Network – IVUN	Contact International Ventilator Users Network (IVUN) for the most authoritative information on living well with ventilator-assistance. Learn about types of equipment, research findings, networking opportunities, and resources for vent users, their families, personal assistants/caregivers, and healthcare providers. Access at www.ventusers.org or contact at info@ventusers.org or +1-314-534-0475. <i>Join to receive regular updates and to support its valuable work.</i> <div style="text-align: center; margin-top: 20px;">  <p style="font-size: small;">IVUN International Ventilator Users Network An affiliate of Post-Polio Health International (PHI)</p> <p style="font-size: small;">Visit ventusers.org 314-534-0475</p> </div>	
Primary Care or Attending Physician*	Oversees your medical care in outpatient and/or inpatient depending on the healthcare system where you live. Needs to be knowledgeable about your various medical conditions and the latest treatment options available to you. Prescribes medications, alternative treatments, and refers you to appropriate specialists as allowed by your insurance benefits or programme provisions.	
Pulmonologist/Respirologist*	Must understand neuromuscular breathing conditions, ventilators, and the latest treatments; be responsive to your needs; and communicate clearly and respectfully. For referrals: info@ventusers.org or +1-314-534-0475 or <i>Resource Directory for Ventilator-Assisted Living</i> at www.ventusers.org/net/VentDIR.pdf .	

Respiratory Therapists (RT) or Nurses (RN)*	Normally, these professionals will manage your ventilator and help to clear mucous from your lungs in hospitals and rehabilitation and long-term facilities. If you have a trach, RTs or nurses will suction you; and teach you and others how to suction, to take care of your trach, and to prevent infections.	
Physical, Occupational, Speech Therapist*	Provide therapy to improve your mobility, functioning, and/or ability to swallow and communicate. Expect these professionals to individualize your treatment based on your conditions and needs. Inpatient, outpatient, and/or in-home services may be paid for by government agencies, programmes, or insurance providers.	
Home Health Equipment Provider*	Provides medical equipment and instructions on their use for ventilator users and caregivers/personal assistants. Expect representatives to be knowledgeable, efficient, and responsive to your needs. Access referrals in <i>Resource Directory for Ventilator-Assisted Living</i> at www.ventusers.org/net/VentDIR.pdf or contact info@ventusers.org or +1-314-534-0475.	
Psychologist/ Social Worker/ Professional Counselor	Assists in identifying your feelings, needs and goals. Guides you in finding ways to relieve distress, adjust to losses, and resolve problems and obstacles to taking action, e.g., living with a vent/trach, family difficulties, self-defeating behaviors. Ideally, hospitals and rehabilitation facilities offer this assistance. Outpatient and in-home treatment available based on insurance, agency, or programme provisions; phone/internet therapy is rarely reimbursed.	
Case Manager/ Coordinator*	Oversees authorized services, in facilities or outpatient or in-home treatment, paid for by agencies, programmes, or insurers. Should inform you of your benefits and submits documentation to gain approval of treatment. Coordinates transitions into next level of care or the community. Contact this person with treatment questions or problems; procedures for service requests (e.g., in-home personal assistants); for copies of reporting and appeals procedures.	
Patient Relations Representative/ Ombudsperson	Intervenes to resolve concerns and complaints from patients, family members, and health representatives about treatment or services provided in a hospital, rehabilitation or long-term facility, or a patient's home. Helps to ensure your treatment meets quality standards.	

*These professionals must understand neuromuscular breathing issues.

Part Two: Really Important People

In addition to the roles of healthcare providers, the roles identified below can make all the difference in ensuring that your healthcare and personal needs are met. If possible, best to arrange these roles in advance. Family and friends often volunteer to assume the **Health Advocate/Surrogate** and the **Hiring and Communication Coordinator** roles. However, consider paying for the hiring tasks, if you don't have a suitable volunteer and can afford to.

Person(s)	Their Roles	Action Needed
Health Advocate/ Surrogate	This person interfaces with healthcare professionals on your behalf. Ideally, understands your medical conditions, desires and needs; can speak for you as needed. Especially important during emergencies, when you have limited air to talk, or are in a hospital. Provides critical information in <i>“Take Charge, Not Chances”</i> forms to health providers. Access at IVUN www.ventusers.org/vume/index.html .	
Communication Coordinator	This person links you with your friends, relatives, supporters; provides them with updates, requests for visitors, appointment drivers, assistance, etc. Ideally, forwards messages via the internet, available website (e.g., www.caringbridge.org) or another form of technology.	
Hiring Coordinator	This person coordinates screening, hiring, and training of personal assistants/caregivers. Requires a skilled, patient, and thorough person who will make several attempts to find individuals who match your needs, if needed. Contacts agencies, friends, local community groups for applicants. Best for you to communicate your needs and preferences in advance, if possible. May research policies/procedures for possible payment of in-home services by agencies or programmes and submit requests. See “Caregiver Resources” websites for hiring guidelines and “Exploring the Option of a Trach” for additional ideas: www.ventusers.org/edu/ExploringOptionTrach6032010.pdf .	
Personal Assistants/ Caregivers	Some individuals using NIV, and especially those using a trach, may need partial to extensive personal assistance. Individuals who are hired need to be well-trained to provide your personal care and perform tasks as you wish: e.g., vent/trach care, infection control, meals, cleaning, bathing. Seek trustworthy, reliable persons with good judgment to protect your health and intervene effectively during emergencies. See “Caregiver Resources” websites for guidelines on screening, selecting, and managing individuals you hire.	
Volunteers	If needed for any assistance, seek volunteers. Contact possible sources: neighbors, friends, relatives; healthcare colleges/programs; local non-profits: e.g., nursing, RT, pre-med students; religious congregations; senior, disability or community organizations.	
Friends & Relations!!	Of course! But sometimes you – or your Communication Coordinator – may need to let them know you’d like to see them... and ... need some help or a visit.	

Sources of Comfort and Energy

Life with continuous use of NIV or a trach will have its limitations. But as when facing all of life's challenges, it helps to think of sources of **comfort, energy or pleasure—even joy!** On the right is space to add notes about action you may want to take about the categories on the left.

SOURCES of Comfort and Energy	EXAMPLES	NOTES
Awareness of Feelings and Needs	Mindfulness, meditation, relaxation techniques, journaling, books/CDs, life coaching, counseling, psychotherapy.	
Supportive Touch	Massage or rub: back, hands, feet, neck; Healing Touch, acupressure.	
Music/Music Therapy	Listening to soothing, uplifting music or a piece that helps to release emotions (e.g., for a good cry). Singing favorite songs. Listening to or playing an instrument.	
Visitors	For laughter, support, loving and meaningful connections, to share mutual interests, spiritual or cultural practices.	
Nature	Access to outdoor air, trees, skies, hills, greenery, flowers, sun, water; or views or artwork of these.	
Just for Fun	Children, the arts, pets, games, movies, sing-a-longs, outdoor concert, sport or community events, books, puzzles, sports.	
Mind-Body Approaches	Yoga, Tai Chi, Chi Kung (sitting), body-centered psychotherapy, acupuncture, deep muscle massage, guided imagery.	
Food for our Body, Mind, Mood	Healthy, tasty fruits, veggies, protein, grains, treats, herbs and spices.	
Spirituality	Spiritual or religious values, practices; prayers, serenity, justice, gratitude, compassion, equality, forgiveness.	
Beauty	Décor/arrangement of living space, colors, fabric, artwork, organization, cleanliness, photos, mementos, fragrances.	

Your Interests	Intellectual, artistic, recreational, the arts, professional/occupational, advocacy, reading, sports, environmental, ethnicity, health-related, politics, news, ancestry.	
Emotional Health	Self-help books, CDs, websites to help reduce distress, improve relationships and quality of life: “Treatment Approach Options Chart” at www.post-polio.org/edu/pphnews/pph19-1p9.pdf or info@ventusers.org or +1 314 534 0475.	

Resources for Information

1. **International Ventilator Users Network (IVUN):** www.ventusers.org Tel: +1-314-534-0475
Ventilator Information: *Home Ventilator Guide* www.ventusers.org/edu/HomeVentGuide.pdf
Referrals to professionals and Ventilator Listservs: *Resource Directory for Ventilator-Assisted Living* www.ventusers.org/net/VentDIR.pdf.
“Take Charge, Not Chances” forms provide healthcare professionals with critical information during emergencies. www.ventusers.org/vume/index.html
2. **Ventilator Users’ Perspectives on the Important Elements of Health–Related Quality of Life,** University of Toronto study for NIV and trach users: <http://www.post-polio.org/res/QofLFINALREPORT-Sept2002.pdf> or Tel: 1-314-534-0475.
3. **Non-invasive Ventilation Options** proposed by John Bach, MD. www.DoctorBach.com/
Book: *Management of Patients with Neuromuscular Diseases* (2004)
Journal Article: “Extubation of Patients with Neuromuscular Weakness: A New Management Paradigm” <http://journal.publications.chestnet.org/article.aspx?articleid=1086434>
Presentation: <http://www.ventusers.org/edu/ConfCall2013Bach.pdf>
4. **“Exploring the Option of a Trach”** article identifies issues to consider in deciding to use a trach and suggestions for living with a trach. It includes a comparison of the Advantages and Disadvantages of Continuous NIV and a Trach. www.ventusers.org/edu/ExploringOptionTrach6032010.pdf.
5. **E-learning modules on trachs:**
 - **West Park Health Centre:** www.westpark.org
www.ltvcoe.com/training_oelib_home.html
 - **Ottawa Rehabilitation Institute:** www.irrd.ca/education
6. **CHEST VIDEO:** Audrey King, long-time vent user, describes her challenges of living with a trach for two years while recovering from an illness. www.polioplace.org/resources/icu-homecare-patients-perspective

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7. **Treatment Approach Options Chart** identifies books and websites on managing stress and improving relationships and emotional health. Suggestions based on learning preferences. www.post-polio.org/edu/pphnews/pph19-1p9.pdf.
8. **Caregivers Resources** are available on national and local internet sites, e.g., “Caregivers Library:” www.aarp.org/home-family/caregiving; www.caregiver.com; www.medicare.gov/caregivers/.