



The Consequences of Not Managing Ventilator Supported Children Noninvasively

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Abstract

“It is difficult to get a man to understand something when his salary depends upon his not understanding it (Upton Sinclair).” Before electricity became widely available after 1930, home mechanical ventilation was not possible. In the 1940s and 50s up to full continuous noninvasive negative pressure ventilatory support was provided by Iron Lungs and other body ventilators [1]. The Danes did not have these in 1952, so tracheotomies were first done for ventilatory support (CTMV). This spread to the U.S. However, in 1953 the mouthpiece CNVS was described by Dr. John Affeldt at Rancho Los Amigos in Los Angeles. In 1957 Dr. Augusta Alba removed 257 patients from body ventilators and placed them on up to continuous noninvasive positive pressure ventilatory support (CNVS) via simple mouthpieces which many used for CNVS for over 50 years and some still do today for 70 years of CNVS without resort to tracheotomies. In 1995 I informed the parents of two boys with spinal muscular atrophy type 1 (SMA1), who were intubated for acute on chronic ventilatory failure, that they would likely be dead in 1 year without tracheostomy tubes since they have no functioning muscle below OR above the neck except for eye movements. These boys are now 30 and 28 years old and we have 16 others between 19- and 30-years old dependent on CNVS without tracheostomy tubes despite having no muscle movement other than for their eyes. For intercurrent respiratory infections and pneumonias we [2,3] and others [4] have been able to extubate these patients with as little as 0 ml of vital capacity (VC) without tracheostomy tubes 100% of the time for, now, well over 100 cases. We also have 4 Duchenne dystrophy (DMD) patients over 50 years of age dependent on CNVS for 30 years, with two never having been hospitalized, and several hundred other DMD CNVS users with none undergoing tracheotomy despite many over age 40. Thus, it is clear that no child needs a tracheostomy tube for only being too weak to breathe, but physicians have to want to learn how to manage them noninvasively. In the U.S., TMV users must have 16 hours per day of nursing care at \$85 per hour or be institutionalized at a cost of about \$1200 per day. CNVS users may not be “entitled” to nursing care since they don’t have foreign bodies through their necks and so are managed by minimum wage personal care attendants sponsored by Medicaid waivers. It has been estimated by extrapolation that New Jersey and New Medicaid may have been spared over \$100 million each by simply avoiding CTMV for the lifetime institutionalization of our local DMD population [5].

So, considering that we spent \$4.7 trillion for health care in the U.S. in 2023 or 6 times what we spend on our military, are rated 37th by the World Health Organization, die younger than in 35 other countries and 7 years younger in countries whose governments spend 1% of GDP for health care rather than our 19%, and spend over \$1 trillion annually for health care administration, considering that 50 to 80+% of CTMV users with neuromuscular conditions die BECAUSE of the tracheostomy tubes, isn’t it time that physicians learn noninvasive management? “I know that most men, including those at ease with problems of the greatest complexity, can seldom accept even the simplest and most obvious truth if it be such as would oblige them to admit the falsity of conclusions which they have delighted in explaining to colleagues, which they have proudly taught to others, and which they have woven, thread by thread, into the fabric of their lives.” Leo Tolstoy, 1828-1910.

Consider the following:

- No one needs a tracheostomy tube for only being too weak to breathe, that is, for people with ventilatory pump failure (VPF).
- People, at any age, can become continuously dependent on noninvasive ventilatory support (CNVS) without ever going to a hospital or developing acute respiratory failure[6].
- CNVS is now being provided for some for over 65 years, and for decades for some from as young as 4 months of age [7].

- d) Noninvasive ventilatory support (NVS) is safer, better tolerated, and better maintains quality of life than does TMV [8].
- e) Bi-level positive airway pressure can be used at NVS settings but rarely is.
- f) The expiratory positive airway pressure (EPAP) of bi-level PAP is counterproductive and potentially harmful for people with VPF [9].
- g) People who depend on CNVS, day and night, are safer at home than in institutions where the tendency is to deliver oxygen that can result in acute on chronic respiratory failure [10].
- h) For people with VPF, noninvasive ventilation should only be used at NVS settings [11].
- i) Clinicians fear barotrauma but for patients without primarily lung disease, this is very rare.
- j) Oxygen therapy is never a substitute for NVS and MIE and should not be offered to people with weak muscles unless intubation cannot be averted by NVS and MIE.
- k) Intubated people who cannot pass ventilator weaning parameters or spontaneous breathing trials because they are too weak to breathe can be safely extubated to CNVS and MIE. 2,3
- l) Children and adults who are CNVS dependent can be discharged home safely once families are taught how to use CNVS and MIE to keep oxyhemoglobin saturation $\geq 95\%$. www.breatheNVS.com centers have done this for over 1000 CNVS dependent individuals.
- m) Tracheostomy mechanical ventilation hinders, and can entirely prevent, ventilator weaning and is associated with 50 to 90% of the mortality of people with some neuromuscular conditions [12,13].
- n) Suctioning via an intubation or tracheostomy tube does not clear the left airways up to 92% of the time, resulting in most pneumonias being in the left lung [14].
- o) Acute and long-term use of NIV and NVS should never be considered other than in conjunction with MIE for patients with cough flows < 300 L/m.
- p) Patients with brain disease wean from TMV when airways are cleared by MIE [15].
- q) You earn money by putting tracheostomy tubes in, not by taking them out.

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