

# Gender in the ICU

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# “Help! My Patient Has Duchenne Muscular Dystrophy”

## How should you handle a chronic ventilator user admitted to your ICU with acute critical illness?

“John is a nineteen year old, first year university student with Duchenne Muscular Dystrophy. He had undergone scoliosis surgery five years ago. For the past two years, he has been confined to the motorised wheelchair, and needs to use nocturnal non-invasive ventilation – S/T mode 16/5, RR 16/min.

He was crossing the road using his motorised wheelchair when he was hit by a slow moving van. He sustained the following injuries: Left humerus fracture; left 5th to 9th rib fractures with left lung contusion; left tibia-fibula fractures.

The Orthopaedics Consultant has decided that his injuries should be treated conservatively.”

Such could be a typical introduction by your resident on a morning in the ICU. Or perhaps, more commonly, it could be that a similar chronic ventilator user is admitted for pneumonia, urinary tract infection, or acute appendicitis. They often end up in intensive care because of their pre-existing need for mechanical ventilation. How should we manage these individuals in a way that is adequate and humane? The following are some suggestions:

**a.** Many chronic ventilator users have managed to order their living arrangements optimally according to their personal limitations. Listen closely to the ventilator user or his/her family members about his/her usual baseline condition, and how he/she orders or organises his/her daily activities and needs.

**b.** Oral intubation in one stroke takes away both oral communication and swallowing, and sedation increases the risk of cognitive dysfunction. Minimise the use of sedation, making sure to incorporate daily awakening trials if deeper sedation is employed. Ideally the ventilator user is pain-free but not

A personal observation and reflection on how to handle a chronic ventilator user and suggestions to smoothen the sojourn of the next chronic ventilator user through an ICU, while ensuring maximal dignity and maintenance of function; minimising suffering and reducing the need for inappropriate withdrawal of life support.

sedated (RASS 0 to -1), and augmentative and alternative means of communication (AAC) are reintroduced (if the ventilator user is already familiar with them) as soon as possible. A speech and language pathologist can help establish communication with AAC.

**c.** Aim to keep the duration of oral intubation as short as possible. In ventilator users with intact bulbar function, and with a current injury or illness not likely to impede breathing, aim to extubate the patient to non-invasive ventilation as soon as possible. The roadmap to a successful extubation was described in the 2010 article by Bach and co-workers. If this doesn't appear feasible, consider an early tracheostomy.

**d.** Not all users of non-invasive ventilation are familiar with the possibilities and limitations of a tracheostomy. Even many physicians think that a tracheostomised patient will never be able to speak verbally or swallow orally. The process of decannulating a chronic ventilator user is very different from that for a tracheostomised person with no respiratory muscle weakness. Getting the opinion of a chronic ventilation specialist would help you to make a better prognostic assessment so necessary for a meaningful discussion with the ventilator user.

**e.** Do not be surprised that the chronic ventilator user may request for “all

resuscitative measures”. A large proportion of ventilator users with disabilities are satisfied with their lives and want to continue living. Shed any “ableist” biases we may have. Recognise that there are inherent problems with using questionnaires like the SF-36 to assess disabled individuals. A disabled person may not be able to walk, but he/she may be perfectly happy going to the mall in the motorised wheelchair.

**f.** In the chronic ventilator user who requests for “no further resuscitation” incongruous with the severity of physical injury or illness, it is helpful to see if there are reversible socio-economic issues that are weighing on them. Often these issues cause fear and uncertainty, and arguably limit the freedom of the individual in making choices.

**g.** Should the chronic ventilator user receive a tracheostomy, once the ventilatory parameters are stabilised, partial or complete cuff deflation can be attempted for the purpose of vocalisation. This is better done using a portable, trach-compatible, life-support turbine ventilator (home ventilator) rather than an ICU ventilator, as the home ventilator has better leak compensating capabilities. Periods of cuff deflation for speech are as important, if not more important than periods of ventilator free breathing, and both should be incorporated into the

routine of rehabilitation of such a patient.

**h.** Understand your portable ventilator. We assume that intensivists would automatically be ventilation experts. Yes, and no. Ventilator manufacturers seem to set as their key performance indicator the ability to devise nomenclature that confounds clinicians. As an example, would I be able to succinctly explain the difference between pressure support mode and spontaneous/timed mode to my resident? Do we really know, or do we think we know?

**i.** Understand the impact of leak on ventilation. Leak is inconsequential in the orally intubated intensive care patient. If there is leak, the machine alarms, and the leak is sealed, one way or another. Leak is ubiquitous in chronic ventilation, whether in individuals on non-invasive ventilation or individuals on cuff-deflated/cuffless tracheostomy using leak speech. How much leak is acceptable? What is the impact of leak on cycling or triggering? Are there work-arounds with regards to leak (by changing modes or adjusting settings for example)? Are there things you can do to the interface to decrease leaks?

**j.** Understand the special requirements for airway clearance. What are the strategies that are essential for people with muscle weakness. Is there a difference in techniques for NIV vs tracheostomised patients. How about individuals with bronchiectasis?

**k.** Organise, train and motivate the team such that there is adequate care round the clock. The ventilator user constantly requires someone who knows how to operate the ventilator (portable ventilator, not ICU ventilator), troubleshoot the interface, perform airway clearance and perform rescue breathing. At home, this is done all year round by just a small number of (two to four) family members or carers. Could it be that in the ICU, we cannot replicate this level of care, even though we have many junior doctors, ICU bedside nurses and a variety of therapists? Do we need to rethink how to break down our silos?

**l.** When allowing tracheostomy cuff deflation and leak speech, part of the inhaled air escapes through the upper airway (indeed this is how vocalisation occurs). As such passive humidification with a heat moisture exchanger may become ineffective. Active humidification with a heated humidifier and inhaled aerosolised saline therapy may be necessary to prevent encumbrance of the airway by dried, thick secretions.

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**m.** Lengthening periods of ventilator free breathing should not impede the rehabilitation of strength and endurance of the chronic ventilator user, aiming to restore pre-illness, pre-injury function. The ventilator can be used during rehabilitative sessions to optimise cardiorespiratory function so that the focus can be on the musculoskeletal training.

**n.** The nasogastric tube can be an uncomfortable and cumbersome appendage. If a ventilator user is extubated to non-invasive ventilation, the nasogastric tube increases upper airway resistance and may also contribute to facial skin injuries. Changing a nasogastric tube by the bedside may be dangerous or impossible in someone dependent on continuous non-invasive ventilation. Even in a tracheostomised patient, the nasogastric tube may be cumbersome and uncomfortable. Whilst the risks of serious abdominal complications with gastrostomies is reported as up to 5%, this risk needs to be balanced against the above-mentioned issues. The gastrostomy can be inserted either endoscopically or radiologically. The radiologic approach is convenient and can be done with minimal

sedation, and is the preferred approach in our institution for chronic NIV users with minimal respiratory reserve.

Upon stabilisation of the acute illness or injuries, it is very helpful to either transfer the patient to a chronic ventilation specialist team (indeed some legislations require this) or to seek the advice of such a specialist team at all phases in the rehabilitative journey of the chronic ventilator user.

These are my personal observations and reflections working both as an intensivist and a chronic ventilation physician. I hope the suggestions are relevant and helpful, and will smoothen the sojourn of the next chronic ventilator user through your ICU, allowing maximal dignity and maintenance of function; minimising suffering and reducing the need for inappropriate withdrawal of life support. Some useful articles for reading are listed in the references.

### Conflict of Interest

None. ■

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