

Clinical Considerations for Neuromuscular Disease (NMD) Patients

ATTENTION CLINICIAN: _____, has a NMD with respiratory muscle weakness and requires mechanical/assisted ventilation and other respiratory muscle aids.

This document is shared in the spirit of positive collaboration and to spread awareness that many treatments that help individuals without NMD may unfortunately harm individuals with NMD.

This individual and/or his or her NMD care team are experienced in NMD respiratory involvement and have learned what does and does not work.

General Respiratory Involvement Info.:

- **Respiratory muscle weakness:**
 - Affects muscles between ribs, diaphragm, and sometimes bulbar (mouth and throat) muscles
 - Can cause orthopnea (discomfort and difficulty breathing while lying down)
A semi-reclined position may be required along with their mechanical ventilation during examination and/or therapy.
- **Mechanical/assisted ventilation:**
 - Assists ventilation (movement of air into and out of the lungs)
 - Corrects oxygen and carbon dioxide gas exchange abnormalities
 - Can be used continuously via a mask, mouthpiece, or a tracheostomy tube
- **Manual and mechanically assisted cough:**
 - Assists a weak and/or ineffective cough
 - Clears airway secretions and can prevent infection
- **Narrow, restricted airway can cause:**
 - Difficult intubation and need for smaller endotracheal tube
- **Reduced lung volume results from:**
 - Areas of micro-atelectasis (small areas of collapse) in the lungs
 - Skeletal abnormalities such as scoliosis (progressive curvature of the spine)

Beware of:

- **Supplemental oxygen** – If given without the individual’s mechanical/assisted ventilation, it can cause:
 - Decreased responsiveness
 - Hypercapnia (an increased level carbon dioxide in the blood and lungs)
 - Suppressed respiratory drive, which can be **life-threatening and cause respiratory arrest**
- **General anesthesia medications** – Certain ones can cause life-threatening complications such as malignant hyperthermia.
- **Narcotics, sedatives, and opioids can cause** - Potentially life-threatening suppression of breathing, especially when mechanical/assisted ventilation is not in use

Discussion with this individual and his or her NMD care team is encouraged.

Notes:
