

Breathing Issues

Some kids with CMD have problems breathing. Problems breathing usually show up either in infancy or as our children become older due to increasing muscle weakness and fatigue. They may also start during a viral illness. Problems breathing may look like disrupted sleep patterns, poor sleep, complaints of headaches, choking while eating and daytime fatigue.

In order to figure out if breathing problems are part of your child's illness, you will be given a referral to see a pulmonologist (lung expert). Many pulmonologists are not used to treating neuromuscular patients. To test for breathing problems that may be subtle, pulmonologists usually order a sleep study to detect if during sleep when our breathing is most shallow, there is a drop in oxygen level or a build up in carbon dioxide. Sleep studies can be challenging in young children as they will be asked to fall asleep in a hospital setting.

Unless there is an overlying problem of pneumonia, asthma or mucous plugging, our kids have less of an issue with oxygen and more of an issue with carbon dioxide retention. Noninvasive ventilation, using either bipap or a volume cycled ventilator with face mask and/or daytime mouthpiece is the treatment for breathing problems.

Additionally, prevention of mucus buildup through a cough assist device, learning to stack breaths and being alert to changes in mucous (phlegm) pattern (color and amount) are important.

There are not many articles in the medical literature regarding the treatment of breathing problems in CMD. Therefore many of the medical articles referenced will be focused on Duchenne muscular dystrophy or ALS (Lou Gehrig's disease). Though the articles pertain to other diseases, the treatments are similar given the underlying problem of weak muscles leading to breathing problems. In both of the diseases above, there has been a shift away from tracheostomy (hole in the neck) placement to noninvasive ventilation using face or nasal masks. This change brings about a significant improvement in patient quality of life with decreased infection risks, but does require active management of mucous.

****Information courtesy of Cure CMD**** ← [create link to curecmd.org](http://curecmd.org)