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**Annual Family Conference 2014**

Health Management for Affected Children

Aha Moments from “Caring for Children Who Have Severe Neurological Impairment” in Respiratory Health Management

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 **Contributing factors to respiratory illness:**
*A) Gastro-Esophageal Reflux (GER)*
Reflux is common in our children because of the weakening of the sphincter at the upper end of the stomach.  Reflux occurs when stomach contents (stomach acid & possible partially digested food) to move into the esophagus.

Symptoms include: aversion to oral feeding, respiratory symptoms such as wheezing and coughing, and severe arching.

Tips:  Give your child more frequent or smaller feeds.  Don't move them around a lot for about 30 minutes after feeding.  If feeding via G-tube or NG-tube make sure they are upright, not laying down.
Reflux can be controlled via medications, fundoplication, or GJ-tube.

1) Medications that can be prescribed for reflux include:  Prilosec (omeprazole), Prevacid (lansoprazole), Zantac (ranitidine) or Reglan (metoclopramide).

2) Nissen Fundoplication (anti-reflux surgery) is the surgical tightening of the junction between the stomach and the esophagus.  This procedure is usually offered when doing the g-tube surgery.   According to Hauer (2013), "Anti-reflux surgery is thought to prevent aspiration and thereby maintain respiratory health in children who have SNI [Severe Neurological Impairment], but studies suggest that ARS may not alter the long-term respiratory problems for some children, most likely reflecting multiple other factors not addressed by ARS" (p. 139). Risks factors of fundoplication or ARS may include:  development of retching or worsening of preexisting retching, gastric distention (bloating), inability to belch, and the surgery itself (Hauer, 2013).

3) GJ-tube (gastrostomy-jejunostomy tube) - is a feeding tube that is placed in the upper portion of the intestine (jejunum) therefore bypassing the stomach.  Downside or disadvantage of a GJ-tube include: 1) the inability to change the tube at home as you can with a G-tube; 2) the feedings need to be administered at a slow rate via a feeding pump and are often needed to be delivered continuously (Hauer, 2013).  When compared to the G-tube with a fundoplication, the GJ-tube is a good alternative and research has shown the outcomes (i.e. rates of aspiration) were similar between two interventions (Hauer, 2013).  One benefit of a GJ-tube over the fundoplication is that children with GJ-tube have less retching symptoms (Hauer, 2013).

*B) Excessive Secretions*
As children progress through the disease process, they begin to produce more secretions. This coupled with the loss of their gag reflex and ability to safely swallow can lead to aspiration events.  According to Hauer (2013), "chronic aspiration of saliva is commonly silent, probably reflecting a volume that is too small to produce symptoms, as saliva from the mouth intermittently enters the airways and lung; this process is often referred to as microaspiration" (pp. 180-181).

Secretion Management tips:
1) For thin secretions (excessive drooling) - use of medicines such as Robinul (glycopyrrolate), Scopolamine (given via a patch that you place behind the ear and change every 3 days), Levsin (hyoscyamine), or Atropine can help decrease the secretions.  Side effects of these drugs include constipation, urinary retention.    Allergies may also cause excessive secretions and the use of antihistamines such as Benedryl (diphenhydramine), Zyrtec (cetirizine), or Claritin (loratadine) may help.
Note:  if secretions are dried up too much, they may become too thick and difficult to mobilize, creating mucous plugs.  Under acute respiratory illness, it may be beneficial to stop these medications to ensure secretions are thin enough to effectively mobilize.  These medicines can be resumed when the child is better and back to his/her baseline.

2) Botox injections- Botox is injected directly into the salivary glands to decrease oral secretions.  Benefit of Botox is that it is not systemic like the previously mentioned medicines. (It only affects the location it is injected in, not the entire body).  Therefore, the side effects of constipation or urinary retention are not present.  Botox must be given by a doctor (usually a neurologist) and is administered usually every 3 months.

3) Chest Physical Therapy (CPT): is a technique used to mobilize or loosen secretions in the lungs and respiratory tract.  It is very helpful in our children because they have excessive secretions and an inability to produce a strong cough to mobilize the secretions on their own.  CPT includes: chest percussion, postural drainage (place child on side or tummy with a pillow underneath hips to elevate hips higher than head.  This uses gravity to move secretions downward to drain), and suctioning.  Note:  excessive suctioning can be an irritant and may increase secretion development.
Chest percussion can be done manually (a respiratory therapist is a good resource to learn how to perform CPT) OR by using the VEST.  The VEST is piece of equipment which produces high-frequency chest wall oscillation to loosen and mobilize the secretions.  It is typically well tolerated by the children.  The VEST is produced by the company, Hill-Rom, who is fabulous to work with and will often place the VEST in the home while waiting for approval of insurance to cover the cost.  The VEST should be covered under Durable Medical Equipment (DME) of insurance policies.  Medicaid also covers the VEST.  A prescription from a pulmonary doctor is needed to get coverage.

***Other equipment to help maintain healthy respiratory status and treat respiratory problems***1) Nebulizer - is a drug delivery device used to administer medicine in the form of a mist inhaled into the lungs.  Medicines that may be used in a nebulizer include:

\*    Bronchodilators (i.e. albuterol, levalbuterol (Xopenex), ipratropium (Atrovent)) -substances that dilate the bronchi and bronchioles and increase the airflow to the lungs.  Bronchodilators work by relaxing and opening air passages to the lungs to make breathing easier.

 Note: Albuterol and Atrovent have different mechanisms of drug actions.  Atrovent can also decrease secretion production, along with treating bronchospasm.   Albuterol and Atrovent combined together (also called Duoneb) have synergistic drug action which makes the treatment more effective.

\*    Inhaled sterioids (i.e. Pulmicort (budesonide) - decreases the development of inflammation and mucus; helps keep the airways open and maintain them.

\*    Inhaled normal saline through the nebulizers help loosen the secretions.

Note:  Giving a nebulizer treatment prior to CPT helps loosen and open the airways, enabling better mobilization of mucous.  Check with a pulmonary doctor for guidance about frequency and use of nebulizer treatments.

*Signs and Symptoms of Respiratory Distress*
1) Increase in respirations (breathing fast and using abdomen to help breathe)
2) Nasal flaring
3) Increase in heart rate  (an increase in heart rate also may occur when fever is present).
4) Decrease in oxygen saturation (Note: Use a Pulse Oximeter to measure oxygen saturation.  Check with doctor about guidelines of when to administer oxygen).
5) Change in skin color (including lips and nail bed color).
6) Fever
7) Change in color of the mucous
Tip:  Buy a stethoscope and learn breath sounds to begin to differentiate between baseline breath sounds and congestion/wheezing.

Reference
Hauer, J.M. (2013).  Caring for Children Who Have Severe Neurological Impairment.  Baltimore, Maryland: The Johns Hopkins University Press.

This information is not intended to substitute for professional medical care. Always consult your Physician.