



# Complex Child E-Magazine

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## The Importance of a Good Respiratory Routine

by Susan Agrawal

Children with neuromuscular conditions, metabolic disorders, and respiratory conditions often spend a lot of time sick with colds and flu each year. While illness is often unavoidable, keeping a good respiratory routine both before and during illness can make a dramatic difference in your child's ability to handle and recover from illnesses without secondary respiratory complications like pneumonia. An appropriate respiratory routine very well may save your child's life, and will certainly improve his or her quality of life.

My daughter spent all of the 2008-9 cold and flu season unbelievably sick. Even the smallest cold—a mere day of a runny nose for her siblings—would last seven to ten days for her, most of it on lots of oxygen. A more severe bug landed her on steroids, antibiotics, or both, and she even developed sepsis from bacteria in her lungs seeping into her bloodstream. Had she not had extensive home nursing and medical technology, she probably would have needed to be hospitalized at least six times.

We spent the spring and summer of 2009 developing an appropriate respiratory routine, which her pulmonologist affectionately calls her “pulmonary toilet” routine. While she has still had many illnesses this year, they are much shorter in duration, with many fewer doses of steroids and antibiotics, and fewer serious complications.

The fundamental respiratory routine contains several elements, including treating underlying issues (asthma, allergies, etc.), keeping the airways open and free of inflammation, keeping the lungs and airways free of secretions through airway clearance techniques, and promoting active coughing.

### **Sick and Well Plans**

A good respiratory routine needs to be done all the time, not just when the child is sick. This is true for two reasons. First of all, it is of vital importance that the lungs and airways are in the best shape possible prior to the onset of illness, meaning that they are as close to optimal functioning as they can get. Secondly, many aspects of a respiratory routine take some training and practice for caregivers to master, and some treatments may challenge a child's comfort level. Practicing on a daily basis keeps the skills up for when they become truly necessary.

In most cases, the Well Plan is just a scaled down version of the Sick Plan. For the Well Plan, you might do each step just once or twice a day, whereas you might do each step every three to four hours for the Sick Plan.

Here is an example of the Well Plan and Sick Plan that my daughter is currently using. It is constantly being tweaked, re-evaluated, and revised as necessary. Your plan may look very different, depending on your child's needs.

### **Well Plan**

- HFCWO Vest treatment twice per day for 20 minutes
- Albuterol by nebulizer once per day in AM with morning Vest session
- Flovent by inhaler twice per day
- Breathing exercises once per day for 15 minutes
- Additional Albuterol treatments (by nebulizer or inhaler) for asthma as needed
- Zyrtec for seasonal allergies as needed
- Oxygen at night 3-4LPM

### **Sick Plan**

- HFCWO Vest treatments every three to four hours for 20 minutes
- Albuterol by nebulizer or inhaler every three to four hours
- Suctioning as needed (as often as every 30 minutes with a runny nose)
- Flovent by inhaler twice per day
- Breathing exercises twice per day for 15 minutes
- Zyrtec as needed
- Prednisolone by J Tube, five day course, as needed
- Antibiotics by J Tube or IV as needed
- Oxygen during the day, a minimum of 2LPM
- Oxygen at night, 3-5LPM

The specific components of these plans will be discussed in the following sections.

## **Respiratory Exercises, Chest Physical Therapy, and PEP Devices**

A fundamental part of any respiratory plan is keeping the airways as free of mucus and other secretions as possible. The traditional way to help mobilize secretions is through Chest Physical Therapy (Chest PT), also called percussion. While it is best to consult a pulmonologist or respiratory therapist for training in Chest PT, a general overview of the technique can be found in this excellent handout from the Cystic Fibrosis Foundation: <http://www.cff.org/UploadedFiles/treatments/Therapies/Respiratory/PosturalDrainage/An%20Introduction%20to%20Postural%20Drainage%20and%20Percussion%201-2006.pdf> Note that this handout also discusses postural drainage (lowering the head below the lungs to allow gravity to assist in removing secretions), a technique that is not appropriate for many children with neuromuscular disorders because it can cause aspiration. Many children really enjoy Chest PT, and it becomes one of their favorite daily activities.

Additional respiratory exercises may be performed to help enhance inspiration, expiration, or trigger a cough. Children who are able to control their breathing may be able to learn some of these techniques, which include forced expiration, huffing, controlled breathing, and other techniques. Younger children and children who are physically incapable of performing these exercises can still do respiratory exercises with assistance, typically using a caregiver's hands to help increase inhalation or prolong expiration. These exercises often require a great deal of training to learn. In many cases, your child's respiratory therapist, and in some cases a physical or occupational therapist, may be able to train you. You may also consult with experts like Mary Massery, who treats children and develops appropriate exercises and plans for each child. You may purchase a training DVD from her website at <http://www.masserypt.com/html/home.html>.

For children with some ability to control their breathing, it may also be possible to use an oscillating positive expiratory pressure (PEP) device, such as the Flutter or Acapella. These devices are relatively inexpensive and easy to use. A child simply inhales and then blows into the device, either normally for mucus clearance or with force for mucus elimination. The device creates vibrations in the airway as well as positive pressure, mobilizing mucus. There are also mask PEP devices (that do not vibrate) that may be used with or without a nebulizer to help loosen secretions.

### **Mucus Clearance Devices (HFCWO Vest and Intrapulmonary Percussive Ventilation)**

Sometimes Chest PT is not sufficient to clear the airways, or cannot be performed by a caregiver due to lack of training or caregiver disability. In this situation, a mucus clearance device may be used to help loosen secretions so they can be coughed out.

There are two different types of devices that are designed to loosen secretions. The most common is a High Frequency Chest Wall Oscillation (HFCWO) Vest, an inflatable vest placed around the torso that rapidly inflates and deflates to loosen secretions. See this previous article on HFCWO Vests: <http://articles.complexchild.com/Dec2009/00173.html>

The second device is called an Intrapulmonary Percussive Ventilation (IPV) device, which uses a mask to deliver fast, short bursts of air that cause the airways to oscillate, thereby mobilizing secretions. While both techniques are effective, many insurers consider IPV experimental and will not cover its use. It can also be difficult to obtain insurance coverage for HFCWO Vests for children with diseases other than cystic fibrosis, but it is possible with a detailed letter of medical necessity.



HFCWO Vest

### **Cough Production Devices (Insufflator-Exsufflator)**

In some cases, children are not able to produce an adequate cough, despite mucus clearance techniques and devices. These children may require an Insufflator-Exsufflator, often called a Cough Assist Device, which simulates a cough by providing alternating bursts of positive and negative pressure into the lungs. These devices may be somewhat uncomfortable for some children, and it often takes some time for caregivers to find the best settings. But in certain children, these devices have a significant effect on the lungs and airways.

### **Nebulized Medications to Promote Airway Clearance (Hypertonic Saline, TOBI and Pulmozyme)**

For certain children, special nebulized medications may assist in removing secretions. The most commonly used is Hypertonic Saline, which uses a high salt solution to draw water into the lungs, thereby thinning mucus and making it easier to cough out. It is known to irritate the airways, thereby triggering coughing in some children. Hypertonic Saline should be used with caution in children with fluid balance issues, such as edema.

TOBI stands for Tobramycin Solution for Inhalation, and is an inhaled antibiotic given by nebulizer. Children with chronic lung infections, such as *Pseudomonas*, may see increased respiratory function with routine TOBI nebs.

Pulmozyme is a very expensive inhaled medication that is used to thin secretions, enabling them to be coughed out more readily. It is an enzyme that is thought to break apart the “stickiness” of mucus. While highly effective in combination with other therapies, it is difficult to obtain insurance coverage for this medication in many cases.

### **Other Medications**

Many other medications may be used to keep children’s lungs clear and airways open. These may include Albuterol or Xopenex, bronchodilator medications that are inhaled through an inhaler or nebulizer to open the airways and calm spasming airways. Children with asthma or bronchospasm may benefit from both preventative and rescue applications of these medications. Another bronchodilator that works in a slightly different way is Atrovent.

Long-term inhaled corticosteroids, commonly including Flovent and Pulmicort, are used on a daily basis to prevent asthma attacks and reduce inflammation in the airway. Other asthma medications, including leukotriene antagonists (i.e. Singulair) and long acting beta-adrenoceptor agonists (i.e. Serevent), may be helpful for some children.

In cases of extreme asthma or airway inflammation, oral or IV steroids, such as prednisolone, may be prescribed to open the airways. These medications are known to cause a wide variety of behavioral side effects in children, but are sometimes necessary.

Children with seasonal or environmental allergies may also benefit from allergy medications to prevent additional respiratory symptoms and asthma attacks. A wide variety of medications are available, both over-the-counter and by prescription.

Children with known bacterial infections, such as a bacterial pneumonia or bronchitis, may benefit from oral or IV antibiotics to clear the infection.

### **Be Prepared**

Having Well and Sick Pulmonary Plans in place can not only improve your child’s overall health, but they can also limit the need for medications like oral steroids and antibiotics. Complications such as pneumonia may be reduced, and hospitalizations may be less frequent.

Talk to your child's pulmonologist and respiratory therapist to help you develop appropriate pulmonology routines for your child. These routines very well may change your child's health and quality of life dramatically.