

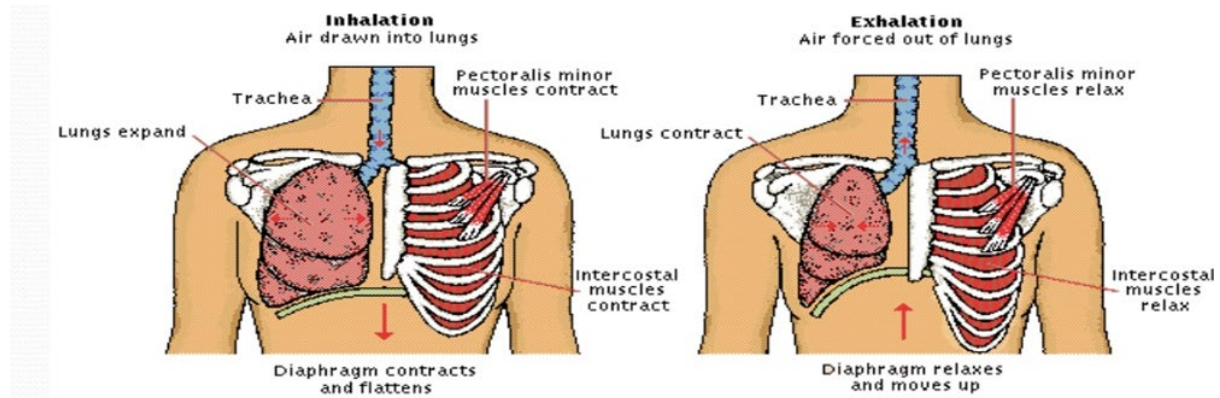
# **Scottish Muscle Network**

## **Patient Information Leaflet**

### **Respiratory Care in Neuromuscular Conditions**

### Can breathing be affected in muscle conditions?

Breathing involves the respiratory muscles, most importantly the diaphragm (the big muscle which is under the lungs) and the muscles between the ribs (the intercostals).



As with other muscles of the body which can be affected by muscle conditions, these breathing muscles can also become weaker over time. This can cause “under breathing” which is when our muscles cannot open our lungs fully to take in and breathe out enough air effectively. It is not that there is anything wrong with the lungs, the lungs still work well, but the muscles that control the amount (or volume) of air that goes in and out of our lungs, can’t do this as well as they used to.

The breathing muscles are also required to help us cough effectively to clear secretions (mucous) from the lungs. When these muscles become weak an ineffective cough results, preventing secretions being cleared from the lungs. In some cases, the secretions can block the small airways in our lungs. If the airways are blocked, the secretions cannot be moved into the larger airways for us to cough them out and clear our lungs. If secretions are not being cleared, they can cause infection and you will need help from your child’s doctor and physiotherapist to get everything moving again.

Respiratory issues in muscle conditions can vary greatly between each child and each condition. It is therefore important that your child receives an assessment and care plan from a specialist physiotherapist which can help keep their lungs healthy and help them manage their breathing if they get a cold or infection.

### Keeping healthy and good chest management

Keeping healthy and taking some precautions can help keep your chest clear and can minimise your child’s chance of getting a chest infection. The following advice can help you look after your child.

- **immunisations:** make sure your child’s immunisations (with advice from your doctor) are up to date and that they receive the flu vaccine from their GP or school every year

- **nutrition:** keeping a healthy, varied, and balanced diet can help to make sure your child's body is fuelled in the right way and ready to fight an infection. If they have any problems with chewing and swallowing, you may need advice from a Dietitian
- **activity:** make sure your child is active by doing their daily stretches, playing with friends and family, joining a club like boccia or participating in a formal activity. This will "exercise" your child's lungs and breathing muscles as well as the other muscles in their body. It is important to encourage the breathing muscles to work a little harder from time to time as this will increase the amount of breath taken in and help expand your child's lungs, increasing the volume of air in their lungs. This helps move the secretions in to the bigger airways and keeps their ribs moving. [See also "Stretches and Activity for people with Neuromuscular Disorders" leaflet]
- **sleep hygiene:** Making sure your child's body gets the rest it needs to recover from the strains of the day is essential. Adequate sleep can improve your child's physical and emotional health. If your child has problems getting to sleep or staying asleep, speak to your Doctor, Nurse, or Physiotherapist. [See also "the importance of sleep" leaflet]
- **hand hygiene:** Try to avoid your child coming into contact with people with colds or chest infections as much as is reasonably practical. Make sure they wash their hands well and often to prevent the spread of infection

## Respiratory Assessment

We can assess your child's respiratory system (breathing muscles and lungs) in a number of ways:

- **physiotherapy assessment:** A respiratory assessment by a specialist physiotherapist may involve listening to your child's chest and feeling the movement of their chest to assess their breathing pattern. It may also involve measuring your child's lung function through peak cough flow and spirometry tests. You may be familiar with these tests if your child attends the North Star clinic or the Neuro-Respiratory Clinic
- **lung function tests:** Your child's Doctor or Nurse may request these tests to assess how well your child's respiratory muscles are working to move air in and out of their lungs. These tests are carried out in the lung lab and involve blowing into a mouthpiece attached to a computer. We use the results to guide treatment and assess if more support is required to make sure the oxygen moves into your child's blood stream well and their body is able to get rid of the waste products (carbon dioxide)

- **sleep study:** At night the weakened respiratory muscles may be more noticeable due to the fact at nighttime our breathing muscles also need to rest. If the muscles are weak and need rest, they may not be able to take in enough air for your child's body whilst they are asleep. We may request a sleep study where we can monitor your child's oxygen levels through the night whilst they sleep. This can take place at home with a monitor on your child's finger, or an overnight stay in hospital if your child needs a more detailed study
- **neuro-respiratory clinic:** Respiratory function is monitored by the Respiratory Consultant and the neuromuscular team at the Neuro-Respiratory Clinic. At this appointment they will discuss your child's respiratory symptoms and explain any test results
- **speech and language therapy (SALT):** Your child may have a Speech and Language Therapy Assessment to check for any feeding or swallowing difficulties. Your child may have a Video fluoroscopy which is a special type of x-ray where we film your child swallowing different thickness of food stuffs and we assess their swallow.
- **scoliosis:** We may monitor your child's spine to pick up on any curving of the spine (scoliosis) caused by weakness of the muscles supporting the spine. We need to monitor this to prevent it affecting the lungs and reducing the space available for breathing

## Breathing exercises, equipment and devices

Your child's physiotherapist may prescribe breathing exercises to help exercise and stretch your child's lungs:

- **incentive spirometry:** these devices encourage long, slow, deep breaths and provide visual feedback to encourage the correct technique
- **bubble PEP:** This involves your child blowing through a tube into water to create bubbles. The result of this is a positive pressure in the lungs helping to open up the small airways and allow better flow between oxygen and carbon dioxide. Younger children may find this a fun activity
- **ambubag:** (or lung volume recruitment) involves your child breathing in through a mask attached to a bag filled with air. As they breathe in, you squeeze the bag to give your child an extra volume of air
- **breath stacking:** involves a series of breaths in without your child breathing out, increasing the volume of air in the lungs beyond that which their muscles are normally capable of. You can also use an ambubag. Breath Stacking can increase the volume of air in your child's lungs which allows for a more effective cough when they exhale
- **assisted cough:** This involves you applying manual pressure to your child's abdomen or chest to increase the airflow out when coughing

- **cough assist or clearway:** These devices work well to support a weak cough and help remove secretions. Your child will have a mouthpiece or facemask over the nose and mouth and air is delivered into their lungs from a machine followed by a quick switch to a negative pressure to empty their lungs. This quick change in pressure mimics a cough and helps to remove secretions from their airways
- **non-invasive ventilation (NIV):** If your child already has NIV, they can use this during the day as a therapy to provide deep breathing exercises.

## Signs of a respiratory problem

If your child develops any of the following symptoms it is important that you contact your GP and follow the guidance in your child's respiratory plan:

- **cough:** an increased cough, particularly a productive cough where yellow or green mucus is coughed up can be a sign that your child has a chest infection. It is helpful to recognise your child's normal secretions and look for changes in colour, amount of mucus and secretions produced and if you notice a change then contact your Doctor
- **temperature:** a temperature, feeling sweaty or feverish may be signs of an infection
- **fatigue:** Increased lethargy from normal, waking up at night or daytime sleepiness
- **breathlessness:** More shortness of breath than normal. This may be more apparent in certain positions e.g. lying down
- **poor appetite:** eating less and not showing an interest in food

## Breathing Support (Ventilation)

Weak respiratory muscles can prevent the lungs taking in enough air and therefore prevent enough oxygen getting around the body. This can often cause symptoms such as fatigue, sleep disturbances, morning headaches, confusion, poor appetite, weight loss, weak voice (i.e. not being able to shout loudly) and weak cough. These may be signs that your child needs more breathing support.

- **non – invasive ventilation (NIV):** When the respiratory muscles need some support, NIV is introduced. This is often bilevel positive airway pressure (BiPAP) whereby air is delivered through a facemask at a positive pressure during the breath in (inspiration) to open the airways in the lungs. The pressure is reduced on expiration to allow the breath out (expiration). NIV is usually introduced at nighttime but can also be used through the day if required
- **invasive:** Invasive ventilation is delivered through a tracheostomy (surgical incision in the windpipe). Air is delivered through a tube rather than through the nose and mouth

**For more information, please contact your physiotherapist**

<b>Name of hospital physiotherapist:</b>	
<b>Name of community physiotherapist:</b>	

### **Further information**

If you have any queries regarding this leaflet, please contact:

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