

APCP Information Spinal Muscular Atrophy (SMA)

Information for Parents and Carers

What is SMA?

SMA affects the muscles that help children to breathe and cough, making it difficult for them to clear phlegm from their airways, referred to as 'airway clearance'. This increases the chance of developing a chest infection

Although every child's symptoms will be slightly different, generally those who are less mobile (non-sitters and sitters) will need more help with airway clearance.

This leaflet outlines some of the treatment techniques and advice recommended to help children with SMA who struggle with airway clearance.

It is important to remember that any treatment routines should be developed by your child's respiratory physiotherapist in discussion with yourself and your child.

Common treatment options

Percussion

A rhythmic clapping or patting of the chest over the rib cage which can be used to help loosen and move phlegm from deep within the lungs to the larger airways, where it can be cleared by coughing or suction.

Percussion can be performed using a cupped hand or with a specially designed percussion cup. It is often performed in different positions such as lying on one side to help move the secretions.

Suction

This is the use of a thin tube and negative pressure to suck phlegm from the mouth or nose.

It is especially useful in children that struggle to clear phlegm independently when they cough and is often used alongside the other techniques described.

Training of how and when to perform suction should be provided by your respiratory physiotherapist or another appropriately trained medical professional.

Mechanical Insufflation-Exsufflation (also known as "Cough Assist")

Mechanical Insufflation-Exsufflation (MIE) can help clear secretions in children with a very weak or ineffective cough.

An MIE machine helps your child to take a deep breath in by "blowing" air into their lungs, quickly followed by a negative or "sucking" pressure that mimics a natural cough.

There are a number of different MIE machines available. The pressures and routine set will be different for each person and machine.

The MIE is often used alongside other techniques such as positioning or suction.

In very young children, MIE can be less helpful or poorly tolerated. Therefore, other techniques may be explored first.

There are other airway clearance treatments available but their usefulness for children with SMA are not as well known. Your respiratory physiotherapist may still consider some of these other treatments if they feel they would be of benefit to your child.

When should Airway Clearance be performed:

- Airway clearance treatment will be different for every child. Individual advice about when and how
 often to perform treatment should be discussed with your child's respiratory team.
- It is important to complete chest clearance routines regularly at home, even when your child appears well. This can help to reduce the risk of chest infections and further respiratory problems, helping to minimise the need for admission to hospital.
- Completing treatments regularly at home will also help to improve your confidence and skill in performing chest clearance techniques. You and your child will become more familiar with their treatment and better able to spot when they become unwell with their breathing.
- If your child is unwell or has increased phlegm on their chest, the amount of airway clearance treatments may need to be increased
- It is useful to have a clear airway clearance plan to guide how treatments can be increased or changed when your child is unwell and when treatment should be moved to within the hospital.

This should be developed by your child's respiratory team in discussion with yourself and your child.

For more information, please refer to Spinal Muscular Atrophy UK

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This leaflet has been produced following a review of relevant literature and where there is lack of evidence, a consensus of expert opinion is agreed, correct at time of publication.



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