NHS
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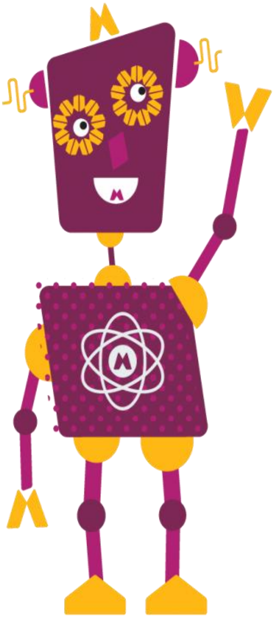
My child needs non-invasive ventilation

Royal Manchester Children's Hospital

'Our Family Caring for Yours'

Introduction

This leaflet is designed to give you information and guidance about taking your child home on non-invasive ventilation. We will discuss training and equipment, home safety and contacts. We know you may be anxious about taking your child home with ventilation, but please be reassured there is a wide multi-disciplinary team ready to support you.



Why does my child need to use a ventilator?

There are many different underlying conditions that could lead to your child needing ventilation support at night when asleep, these can include obstructive sleep apnoea or muscle weakness. Ventilation support at night can help if your child has been suffering from symptoms such as headaches on waking, sleepiness during daytime hours or while at school, and it can reduce any disruptions to sleep, ensuring improved sleep quality. The ventilation can be administered via a non-invasive route using a face-mask interface (these can include masks that cover just the nose, the nose and mouth or the full face). Before starting any overnight ventilation your child will have an overnight sleep study (Polysomnography), which can take place either at home or in hospital, this test will show us what happens to your child's respiratory effort when they are asleep (see information sheet on overnight sleep studies). Once the study has been reviewed, the medical team will decide whether your child would benefit from non-invasive ventilation overnight, to help support their respiratory effort, this will be administer via a mask and they will discuss with you the method for starting this ventilator support.

What is a ventilator?

For the purposes of NIV we use machines that support children's breathing which are portable (unlike a ventilator in intensive care which must remain in the ward/hospital). Some portable ventilator work on internal battery supply others need to be plugged into the mains and uses technology to help support children's breathing. It does this by blowing either air or a combination of air and oxygen into a child's lungs at a set pressure and speed/rate to support a child's respiratory difficulties.
There are many different ventilators used for NIV and the type of ventilator used will be determined by how dependant a child is on the respiratory support. The most common machines used at RMCH are listed below:

The VIVO 1+3

The NIPPY 4

The Dreamstation

What do BiPAP and CPAP mean?

The medical team will decide what level of support your child requires and will complete a prescription. The support required can either be via Continuous Positive Airway Pressure (CPAP) or Bi-Level Positive Airway Pressure (BiPAP). CPAP support means a continuous level of ventilation will be provided to your child, to help keep the airways open, and your child will continue to breathe themselves on top of this support. BiPAP support means your child will receive support of breathing in (inspiratory positive airway pressure or IPAP) and breathing out (expiratory positive airway pressure or EPAP). The prescription and any changes made to the ventilation settings for your child will be directed by the medical team.

The Equipment

Once the decision has been made to start ventilation, your child will be measured for an appropriate size mask and be given a ventilator. You will be taught how to use and look after the ventilator at home, including when to wash the tubing and change the filters. The staff on the ward will support you through the process of explaining the equipment to your child and showing you all how to use the equipment, and you will stay overnight for a repeat sleep study to confirm that the ventilator support is appropriate before being discharged home.

Going home

We understand that it is daunting going home with new equipment, however there are many people who are here to help you. You will be referred to your local Children's Community Team (CCN team) who will be able to order in all the equipment you require for home, but will also be available to support, answer any worries you have and to visit you at home. You can also call Ward 83 at Royal Manchester Children's Hospital, if you have any other queries.

Frequently asked questions…

Will my child need NIV forever?

This is a common question asked by families. It depends heavily on the reason for NIV for your child. Generally those children who start NIV due to prematurity or structural airway issues such as malacia often do not need NIV beyond pre-school years, however children who have started NIV later in childhood or who are on NIV for muscle weakness often require the support lifelong. The best approach is to ask either your consultant or LTV advance nurse practitioner

Does NIV stop my child learning to breathe for themselves?

NIV is a supportive treatment which does not prevent your child either from breathing for themselves or learning to breathe for themselves. It helps improve your child's breathing pattern or depth of breathing or order to improve their quality of life.

Will NIV make my child weaker?

Commonly people think that using NIV will either make their child weaker or lazy or reduce their muscle strength, however the converse is true. Using NIV for children often helps support children's respiratory muscles and improves their level of alertness and strength. It does this by relieving the "extra" work a child would have to put in to sustain or manage their own breathing.

My child is refusing to wear the mask?

In this instance if possible, it is useful to know if it is the mask that they dislike or the ventilation. If it is the ventilation, then you should contact the LTV team at RMCH as we may be able to change the settings on the ventilator to try and make more wearable.
If it is the mask, then it would be worth trying to work with your child, let them play with the mask and maybe wear it when it is not attached to the ventilator so they

get use to the feel of the mask before going to bed.
It is always useful to make putting on the mask part of the night-time routine, and the use of a reward chart may also make a difference.

What do I do if my ventilator is broken?

Your ventilator belongs to Royal Manchester Children's hospital, therefore if you have any problems with the ventilator at home, it breaks or needs servicing then you need to call Ward 83 at Royal Manchester Children's Hospital who can arrange for you to come and collect a replacement.

What do I do if my mask is broken?
If your mask breaks or you feel the mask is getting too small for your child, then you should contact your local Children's Community Team (CCN team) who can organise ordering a replacement for you.

What do I do if the mask starts to mark my child's face?

Sometimes the mask can leave a mark on your child's face (usually across the bridge of the nose or the cheeks) this may be a sign that the mask is too small or that it is on too tight, or you may need to use some protective tape under the mask. You should contact your Children's Community Team (CCN team) who can arrange to visit and review and will be able to offer advice.

Useful Numbers

NIV Specialist Nurse: 07811592235
Discharge Nurse: 0161 7012111
Ward 83 Educators: 01617015697
Ward 83: 0161 7018301or 0161 7018309

Useful Links and contacts

British Lung Foundation
The BLF provides support and advice.
Helpline 0300 003 0555
Website: www.blf.org.uk

Wellchild the national charity for sick children
For family support and help
Helpline: 01242 530007
Website: www.wellchild.org.uk

Bliss
Bliss is a UK charity that cares for premature and sick babies
Helpline: 0207 3781122
Website: www.bliss.org.uk

No Smoking

Please protect our patients, visitors and staff by adhering to our no smoking policy. Smoking is not permitted in any of our hospital buildings or grounds, except in the dedicated smoking shelters in the grounds of our Hospital site.

For advice and support on how to give up smoking, go to www.nhs.uk/smokefree.

Translation and Interpretations Services

It is our policy that family, relatives or friends cannot interpret for patients. Should you require an interpreter ask a member of staff to arrange this for you.

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