NHS
Manchester University
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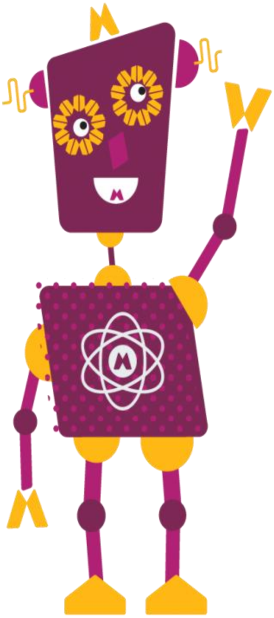
My Child needs Long Term Ventilation

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 long term 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 underlying conditions that could lead to your child requiring the use of a ventilator long-term, but essentially it is because they are unable to maintain their own respiratory function without support. 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, and you will be updated by the team daily on the ward.

Which children need LTV?

Children need LTV for a variety of reasons but primarily because of respiratory failure, or an inability of a child to be able to manage their own breathing. Some children only require respiratory support at night when they are asleep, and others may need this support 24hours a day. Some of the more common reasons for needing LTV are muscle weakness, airway (structural) problems, prematurity and neurological problems preventing the child from breathing effectively for themselves.

What is a ventilator?

For the purposes of LTV we use machines that support children's breathing which are portable (unlike a ventilator in intensive care which has to remain in the ward/hospital). A portable ventilator can work on internal battery supply or 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 a many different ventilators used for LTV, at RMCH we use the Nippy 4+

What does the term invasively ventilated mean?

Invasively ventilated means that your child requires long term ventilation administered via a tracheostomy. A tracheostomy is a breathing tube which is surgically placed in your child's airway, this procedure is undertaken by an ENT specialist, who will discuss the procedure with you.

Looking after your child's tracheostomy

You will be taught how to care for your child's tracheostomy by both the Tracheostomy Nurse Specialist and the team of nurses on the ward. You will be shown how to provide daily cares, such as changing the tapes, as well as how to deal with an emergency situation. This training will be given to all who will care for the child at home.

The Equipment

Your child will require equipment both to care for the tracheostomy and the ventilator, to be with them at all times. This will be daunting at first, but the multi-disciplinary team will show and teach you how to complete, all the care your child will require. The parent educators will work with you to provide a teaching package which can be organised around you as a family.

Parent Educators

The Parent Educators are based in the Wellchild Better at Home Suite on Ward 83 and their role is to facilitate the training of parents and equip them with the knowledge and skills needed to care for their child once discharged home. The Parent Educators also facilitate the training of carers who will work alongside the parents in the home following discharge.

Learning to look after your child's ventilator

Your child will be given two ventilators to go home with; these will be provided by Royal Manchester Children's Hospital. You will be taught how to look after the ventilator and complete the weekly changes of the tubing etc. If you have any problems with the ventilator at home, or the ventilator needs servicing then you will contact Ward 83 Royal Manchester Children's Hospital, who will be able to provide you with a replacement.

Getting ready to go home

Getting prepared to go home can be a difficult time, and we have a Discharge Lead Nurse who will help support you through this journey.

Your home will need to be assessed by an Occupational Therapist to ensure it is suitable for all the equipment you will need at home. This will be completed as soon as your child is stable on the ventilation. Once we know your home will be suitable, we will involve your Children's Community Team (CCNT) who will help with the planning for home. They will discuss with you the support you will require once you get home, and complete an assessment; this will determine if you are eligible for a care package (nurses or carers coming to your house to help you look after your child).

Your Discharge Nurse will organise regular planning meetings to involve the agencies that will care for you once you are home. You will also have the opportunity to go on short home leave, beginning with day trips and building up to overnight leave before you are discharged finally.

Going home

A final discharge date will be arranged by the whole team involved, and this will only be set once you as a family are fully ready for discharge. On the day of discharge, you are likely to be in contact with your CCN team who will arrange to visit as soon as possible once you are home. Once discharged you will be given a list of contact details for those who can support you, and an outpatient’s appointment will be arranged in the Long Term Ventilation clinic at RMCH.

Respiratory Action plan (RAP)

A respiratory action plan will be drawn up by your medical team before discharge, this will list all the steps you should follow in an emergency or if your child’s condition changes at home. You will be given a copy of this before discharge.

Frequently asked questions…

Will my child need LTV forever?

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

Will LTV make my child weaker?

Commonly people think that using LTV will either make their child weaker or lazy or reduce their muscle strength, however the converse is true. Using LTV 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.

Does LTV stop my child learning to breathe for themselves?

LTV 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.

What support will I get?

The level of support you will get at home will be determined by your local CCN team once a full assessment has been completed. This will be discussed with you thoroughly and the team at RMCH can support you through the process. Once home you can always contact Ward 83, if you have any worries or concerns.

Will be child still be able to go to school/nursery?

Yes your child will be able to attend school and nursery, but they will need to have someone who is trained in all the cares they require to be with them all the time. If your child is school age on discharge, the school will be involved in all the discharge planning meetings to ensure a smooth transition. It may be that your child will need to build up the hours of school slowly, but this can all be discussed at the time.

What do I do if my child gets a cold?

You will need to follow your Respiratory Action Plan for any changes to your child's condition at home, and always call 999 if you are concerned in an emergency.

Can we go on holiday?

If you would like to go on holiday, this will need to be discussed with your consultant on an individual basis as there may be further investigations that will need to be carried out before agreement, for example if you would like to fly, your child will require a fitness to fly test.

Can my child go swimming on LTV?

Although not easy this is possible, many families have taken their children swimming with tracheostomies and ventilators, discuss this with our OTs and clinicians if it is something you would like to do.

What do I do if my ventilator is broken?

If your ventilator breaks or requires a service then you need to call Ward 83, at RMCH who will be able to provide a replacement ventilator for you at home via a courier service. You can call

24 hours, a day 7 days a week.

Where do I get all the equipment I need at home?

The consumable equipment you require at home will be provided by your CCN team; on discharge they will be given a list of equipment that they will need to order for you, and be able to provide a delivery schedule.

Keeping things normal

The care your child requires daily will seem daunting at first, but the nurses/carers on the ward will be able to help get you into a routine that will be able to support both yourselves and your wider family. The ward team will complete a partnership in care document with you shortly after your transfer to the ward, and this will help you go through those everyday routines for you and your child.

How will we cope?

We appreciate that looking after a child requiring invasive ventilation can be a great amount of work and increased stress on yourselves and your family, but you will have a large multi-disciplinary team working with you, and we ask that you be honest and open about your feelings, so that we are able to help and provide any extra support you may require. We will also be able to provide you with parent/carer support groups that you can access.

Useful numbers

LTV Specialist Nurse - 07966675783

Complex Discharge Nurse – 0161 7012111

Parent Educators – 0161 7015697

Ward 83 – 0161 7018309 or 0161 7018301

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

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