Introduction

The number of children and young people on long term ventilation (LTV) in the UK is increasing significantly each year. LTV involves the institution of ventilation either invasively, via a tracheostomy, or non-invasively, via a mask delivering ventilation or continuous positive pressure (cpap) for all or part of the day. The aim of LTV is to improve survival and quality of life and for the majority, this can be achieved within the home environment. These patients are frequently complex with varying underlying medical conditions that require input from multiple medical specialities. This also means that the number of conditions for which they may require medical input are often numerous and range from common paediatric illnesses and injuries to complex problems relating to their co-morbidities as well as those relating to their LTV.

LTV care structure in the Yorkshire and Humber region

Local practices vary within Yorkshire but the tertiary centres, Sheffield Children's Hospital (SCH) and the Leeds Children's Hospital, provide the majority of inpatient care of LTV patients regardless of the medical reason for their hospitalisation. Some district general hospitals (DGH) in the region do admit children on LTV but this is dependent on:

- ✓ The hospital
- ✓ The reason for admission
- ✓ The individual patient

With a dependence on tertiary centres, and specifically a large reliance on high dependency care, this provides challenges for the future as numbers of children on LTV continue increasing.

Aims

This guideline has been agreed by members of the Yorkshire and Humber LTV acute pathway working group, a subgroup of the LTV working party, which has representation from multidisciplinary team members in the region's district general and tertiary hospitals. It is intended to be used as a working document for all hospitals in Yorkshire and Humber who have children on LTV living in their area.

The aim is to clarify procedures in the event of admissions for:

- ✓ Acute respiratory illness
- ✓ Non-respiratory illness
- ✓ Injury

This guidance also includes information on:

- ✓ Mechanisms for providing LTV advice across the region
- ✓ The threshold for transfer to tertiary centres from district general hospitals

Individualised Care Plan

The following guidance should be used *in addition* to the individualised care plan (ICP) which every child and young person on LTV *must* have. Parents should all have a copy of this plan but if they do not then there may be a copy with their local hospital, otherwise it can be accessed from the electronic records in their tertiary centre.

Respiratory illnesses

In the event of a respiratory illness all patients on LTV should follow the home care guidance in their ICP. Monday to Friday and within working hours, families can contact their LTV nurse specialists for advice. Contact details for the LTV nurses are documented in the ICP.

Parents or carers should call 999 if:

- ✓ Patients are not maintaining saturations on the rescue settings on their ventilator

AND/OR

- ✓ They have followed the emergency care plan in the ICP and there has been no improvement

Families should take a copy of the ICP to hospital. Practice may vary but the Yorkshire Ambulance Service will usually take LTV patients to their nearest hospital. In some regions there is an ambulance alert system that informs receiving hospitals that a child with LTV is due to arrive allowing appropriate staff to attend ED if necessary. This is not consistent across Yorkshire and Humber and therefore in normal working hours, if possible, families are encouraged to call their LTV nurse and/or their usual hospital ward staff to inform them of their child's transfer to hospital. Outside these hours and if possible, parents should call the ward if their child is well known to them.

In the event of an emergency, LTV patients should be assessed in the Emergency Department and should not go straight to the ward, even if they do have open access.

Criteria for the Transfer from District General Hospitals to Tertiary Centres

Most children on LTV who have a respiratory illness requiring admission are managed in their tertiary centre. A few of the region's DGHs will manage LTV patients but this is for a small number of children who are selected on a case by case basis.

The criteria for transfer from a DGH to a tertiary centre are:

- ✓ A rising CO_2 or worsening baseline function despite best management
- ✓ No improvement/ being static despite intervention
- ✓ Management is exceeding that recommended by the individual care plan
- ✓ Neuromuscular patients requiring ≥30% oxygen
- ✓ The need for additional physiotherapy input

In all cases an early discussion with the tertiary centre is encouraged to facilitate transfer if this is deemed necessary.

The escalation of LTV patients to a Paediatric Intensive Care Unit (PICU) should occur as per the criteria for any sick child.

Non-respiratory illness & injury

In the event of non-respiratory illness and injury, it is acceptable for children to be cared for in their local hospital if that hospital is able to do so safely with appropriate equipment and staffing. This can be assessed on a case by case basis. In some of the region's hospitals, carers are able to support nursing staff but this is dependent on local arrangements.

Advice

The ICP contains information about the patient's medical issues and outlines steps to be taken at home if the patient becomes unwell.
Within working hours, the LTV clinical nurse specialists can be contacted by patients and medical teams for additional advice. Their contact details are recorded in the ICP.

Local teams can contact the on call paediatric respiratory consultant in their tertiary centre for medical advice from Monday to Friday 9am to 5pm. If critical care advice or transfer is required, the Embrace team should be contacted.