

# Commissioner's Guide to NCEPOD Report

## Children and Young People on Long-term Ventilation

### Introduction

#### What is long-term ventilation

Long-term ventilation (LTV) refers to various types of respiratory support provided every day for a period of at least three months. Ventilation is delivered either via a tracheostomy tube (invasive) or via a face mask or nasal cannula (non-invasive). The aim of LTV is to improve survival and quality of life in people with conditions that have led to respiratory failure. It generally involves applying two levels of pressure, one on breathing in and one on breathing out (bilevel positive airway pressure ventilation), although continuous positive airway pressure, commonly known as CPAP might also be used, often to overcome upper airway obstruction.

To date the actual number of people receiving LTV in the UK is not known, as there is currently limited local or national data collection, and no national procedure code for LTV. Where data have been published, it shows that the number of children and young people reported to be receiving LTV in the UK increased from one in 1975 to almost 1,400 in 2013. This is considerably lower than the number identified in this study, and which was still believed to be an underestimate.

The LTV population ranges from small, often premature, babies, requiring support for lung, airway or central nervous system problems they were born with, to older children and young people with failing respiratory or neuromuscular function. Whilst people on LTV often have multiple comorbidities and/or life-limiting conditions, their overall survival has improved and now more people transition from child to adult services and are living for many years.

Advances in ventilator technology, and improved familiarity with the concept of delivering care at home may have helped to make the decision to initiate LTV easier, but delivering this relatively complex care, particularly outside of a hospital setting, has remained a challenge.

#### How are LTV services designed?

The organisation of LTV services varies widely across the UK. LTV (both paediatric and adult) is generally initiated in hospital. There are a small number of hospitals in which LTV care is co-ordinated, but no standard definition of what this entails is available, therefore the exact number of hospitals that would be classified as 'LTV centres' was unknown at the start of the study.

#### What are the issues in providing LTV?

The issues related to the provision on LTV vary, as the range of ventilator support required varies from person to person. Some people require overnight non-invasive ventilation only, whilst others are unable to breathe at all without a ventilator, and may require a tracheostomy tube to connect to it (this group generally has more complex challenges, with more potentially serious complications).

Provision of care outside of a hospital setting, in particular for people with a tracheostomy, often requires adaptation of the home environment, and complex care packages. Inconsistencies in the care packages offered to families have been reported. Despite these challenges, it is widely accepted that people on LTV and their families benefit enormously from being at home rather than prolonged stays in hospital. Children who spend extended periods of time in a hospital setting have been shown to experience developmental and psychological challenges, moreover many caregivers express a preference for home care.

Some people may require escalation of ventilator support over time, 'stepping-up' from non-invasive to invasive ventilation. Conversely others may be 'stepped-down' from invasive to non-invasive ventilation. The knowledge and skills to deliver this treatment has implications for the organisation of

LTV services as well as for training for those involved, both in the community and in all hospitals to which people may present, not just LTV centres.

Discharge arrangements have been highlighted as a key area in a recent systematic review of the experiences of children and young people living with respiratory assistance. Poor discharge planning was reported to lead to insufficient community staffing and training. This led to gaps in overall care packages, nursing support and continuity of care. The training of healthcare professionals and parent carers is therefore an essential part of the discharge pathway. Often different funding streams required to plan and co-ordinate discharge added to the complexity of the process. Published work has also highlighted that as well as socioeconomic factors, accessing short break/respite care is an issue facing those who care for children and young people on LTV.

However, it is not all negative. An ethical framework which supports the decision-making process for LTV has been proposed. This is a positive move for people on LTV, their families and the healthcare professionals caring for them, as it will help ensure that life-changing decisions are centred around the person's best interests.

This document has been created with a view to guiding commissioners/service planners through the report and its findings, to ensure that it can be easily referenced and cited when thinking about organising and implementing arrangements for the care of this patient group.

## **Patient population**

Data was collected on patients up to their 25th birthday who were receiving, or had received, long-term ventilation from the 1<sup>st</sup> April 2016 – 31<sup>st</sup> March 2018. Long-Term Ventilation was defined as 'ventilation provided every day for 3 months (invasive and non-invasive) where the intention is/was to maintain the patient at home on continued ventilator support (not home oxygen)'. From the whole study population a smaller group was sampled for more detailed review.

## **Key issues**

Formalisation of the service planning and commissioning of LTV services through an integrated network of care providers is required. The aim would be to reduce variability in access to areas such as therapy services in and out of hospital, facilitate discharge, enable respite care and simplify how ventilator equipment is purchased and serviced.

Improved access to an appropriate multidisciplinary care team is needed to ensure people on LTV and their parent carers can be supported in the community as well as during an admission to hospital.

Templates for Emergency Healthcare Plans should be developed and standardised for people receiving LTV. They should provide information about what to do and who to contact in an emergency situation. They should form part of hand-held records that are fully accessible to the person receiving LTV, parent carers and the health and social care teams.

Active discharge planning should start at the point of an admission and include all relevant members of the integrated care network to enable a prompt and safe discharge home or to other community services. The discharge plan should reflect any changes in respiratory care.

Transition planning should minimise disruption and prepare for any necessary changes that will occur. Effective leadership for planning transition of care should be encouraged to ensure children access adult LTV services easily. There should be no gap in the provision of LTV care.

## **Benefits of commissioning services for Children and Young People on Long-Term Ventilation**

### **Preventing unnecessary hospital admissions**

Standardised commissioning arrangements and improved coordination between child and adult services will likely afford the growing number of LTV patients transitioning to adult services continuity in the level of care they will receive in the adult world. While reducing variation in discharge care packages and enhancing the role of non-acute care services, could potentially lead to a reduction in the number of unplanned/unnecessary admissions to acute care. The provision of effective community and clinic based care is vital to providing these patients with a preventative, opposed to a reactive, care pathway.

### **Multidisciplinary team provision**

Ensuring all patients have access to a multidisciplinary team of healthcare professionals ranging from AHPs, nurses, psychologists, specialists, commissioners, and an identified medical lead, will improve the process of decision-making by ensuring all those who have a part to play in the patient's care are actively involved and appropriately communicated with. Coordinated care by an MDT will allow for more informed and holistic approaches to the patient's LTV needs which will aid patient outcomes.

### **LTV training provision**

Healthcare professionals and patients highlighted the strong need for a structured training programme and associated resources for long-term ventilation which prepares people on LTV and parent carers for home care, their community providers for routine care and non-specialist clinicians for hospital admissions. In both an inpatient and community environment, confidence and competency in handling these patients', often, complex routine care has huge impacts on their overall outcomes. Patients (when suitable) and all those who are likely to care for these patients need to have access to appropriately resourced training to ensure a high level of competency.

## **Key features of a service**

Ensure service planning/commissioning of integrated care pathways for long-term ventilation services includes formal contract arrangements and local standardisation where possible. These arrangements should bridge child and adult health as well as social care services, respite care and any other partnerships relevant to the local network. Networks should map commissioning arrangements to ensure integration and consistent standards of care and national commissioners should provide a forum to ensure that long-term ventilation provision is considered collectively and delivered to agreed standards.

Ensure that it is possible to identify all people who are receiving long-term ventilation:

- a) Locally this should be achieved by implementing/maintaining a database as soon as possible
- b) Nationally this should be achieved by developing procedure codes for long-term ventilation to bring together the local data collection and support a national database to quantify service provision and facilitate quality improvement

Ensure efficient care planning and discharge by providing a multidisciplinary team as part of an integrated care pathway.

This team should work across community and hospital networks of care for child and adult long-term ventilation services, have an identified clinical lead and include as a minimum:

- a) Medical and nursing staff
- b) Physiotherapy
- c) Speech and language therapy
- d) Psychology

Where applicable

- e) A specialist in tracheostomy care
- f) Palliative care/hospice care
- g) Local service planners/commissioners

Undertake shared decision-making at the point of long-term ventilation initiation, particularly if it is likely to be a life-long therapy. The decision-making process should include input at all stages from:

- a) Children and young people (where ever possible)
- b) Parent carers
- c) The multidisciplinary team (MDT) listed in Recommendation 3
- d) The person's general practitioner whenever practical/possible
- e) Palliative care when appropriate

The process\* should also include:

- f) Discussions over a period of time to ensure decisions are thoroughly considered
- g) Input from independent healthcare professionals for peer review/mediation as required
- h) Provision of approved written and/or online information
- i) Support from other families with a child on long-term ventilation should be considered

*\*A nationally agreed decision-making and ethical framework for long-term ventilation care as proposed by Ray et al should be considered to aid the process. This should involve children, young people and their families as key partners in any development*

Ray S et al. 2018. Towards developing an ethical framework for decision-making in LTV in children. Archives of Disease in Childhood. 103(11): 1080–1084

Ensure that the planning for transition from child to adult services, including the provision of joint transition clinics, has clearly identifiable clinical and executive leadership and forms part of an integrated care pathway for people on long-term ventilation. Developmentally appropriate and patient-centred Transition planning should commence at latest by the age 14 years

Standardise arrangements for long-term ventilation equipment including:

- a) Purchasing
- b) Servicing
- c) Consumables

Standardise templates for personalised Emergency Healthcare Plans for all people on long-term ventilation. They should:

- a) Be easily accessible by all members of the care team
- b) Be clearly laid out so that information can be easily recognised by all members of the care team
- c) Be reviewed at least annually, and after every hospital admission, by the clinical team and the service user/parent carer
- d) Form part of any hand-held records e) Include a fast-track admission plan

Ensure high quality discharge arrangements for people established on long-term ventilation who are admitted to hospital. Planning should:

- a) Commence on admission
- b) Be clearly documented in the case notes
- c) Include the community and usual LTV team
- d) Document any actual or anticipated changes to respiratory care

### **National guidance and reports**

NHS England. Hospital to Home Guideline.

<https://www.england.nhs.uk/urgent-emergency-care/hospital-to-home/>

The Regulation and Quality Improvement Authority. 2015. Guidelines and Audit Implementation Network (GAIN). Audit of discharge of children on long term ventilation

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The Quality Review Service (formerly West Midlands Quality Review Service) LTV Quality Standards. 2018. Services Providing LTV for Children and Young People

<https://qualityreview servicewm.nhs.uk/standards/page/2/>

NHS England. Eo7/S/C Service Specification. Paediatric Long Term Ventilation

<https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/01/e07-spec-paedi-long-ventilation.pdf>

Hospice UK. 2016. Hospice care in the UK 2016: Scope, Scale and Opportunities

<https://www.hospiceuk.org/docs/default-source/What-We-Offer/publications-documents-and-files/hospice-care-in-the-uk-2016.pdf?sfvrsn=0>

The National Confidential Enquiry into Patient Outcome and Death. 2014. On the Right Trach?

[https://www.ncepod.org.uk/2014report1/downloads/OnTheRightTrach\\_FullReport.pdf](https://www.ncepod.org.uk/2014report1/downloads/OnTheRightTrach_FullReport.pdf)

National Tracheostomy Safety Project. 2014. Comprehensive Tracheostomy Care: The National Tracheostomy Safety Project Manual

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The Royal College of Paediatrics and Child Health. 2019. NHS Long Term Plan – A summary of child health proposals

<https://www.rcpch.ac.uk/resources/nhs-long-term-plan-summary-child-health-proposals>

The Royal College of Physicians, London. 2014. Young Adults and Adolescents Transition Project

<https://www.rcplondon.ac.uk/projects/young-adults-and-adolescents-transition-project>

National Institute for Health and Care Excellence. 2016. Transition from Children's to Adults' Services for Young People using Health or Social Services

<https://www.nice.org.uk/guidance/ng43/resources/transition-from-childrens-to-adults-services-for-young-people-using-health-or-social-care-services-pdf-1837451149765>

NHS England. 2018. Commissioning for Transition to Adult Services for Young People with Special Educational Needs and Disability (SEND)

<https://www.england.nhs.uk/wp-content/uploads/2018/07/send-quick-guide-commissioning-transition-adult-services.pdf>

Alder Hey Children's Foundation Trust. 2019. 10 Steps to Adult Services: Transition

<https://10stepstransition.org.uk/>

National Tracheostomy Safety Project. 2019. Patient & Family Resources

<http://www.tracheostomy.org.uk/patient-family-resources>

The Global Tracheostomy Collaborative. 2018. Patients & Families Resources

<https://members.globaltrach.org/collaborate/patients-families-portal/patients-families-resources>

General Medical Council. 2008. Consent: patients and doctors making decisions together

[https://www.gmc-uk.org/-/media/documents/Consent\\_English\\_0617.pdf\\_48903482.pdf](https://www.gmc-uk.org/-/media/documents/Consent_English_0617.pdf_48903482.pdf)

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