CHILDREN AND YOUNG PEOPLE ON LONG-TERM VENTILATION

A review of the quality of care provided to children and young people aged 0-25 years who were receiving long-term ventilation

Recommendations
The aim of the study was to identify remediable factors in the care provided to people who were receiving, or had received, long-term ventilation (LTV) up to their 25th birthday between the 1st April 2016 – 31st March 2018
Data were collected from a number of sources:

1. Number of children and young people on LTV during the study
   - All patients under the care of an LTV service, or who were admitted to any hospital over the two-year study data collection period - 1st April 2016 to 31st March 2018 inclusive.

2. Sampled study population for the clinical peer review process
   - Lead clinician questionnaire
   - Community team clinical questionnaire
   - Acute admission questionnaire
   - Tracheostomy insertion questionnaire
   - Case notes
Study method

• 3. Organisational data
  • Paediatric services
  • Adult services

• 4. Service user and parent carer online survey and focus groups
  • Online survey
  • Focus groups

• 5. Health and social care professional online survey and interviews
  • Online survey
  • Interviews
Data returned: Number of CYP receiving ventilation

3,738 children and young people identified as receiving LTV

126 people excluded as not on LTV
551 people reported more than once

3,061 people on LTV between 1st April 2016 and 31st March 2018
Data returned: Sampled study population

- 3,061 people receiving LTV (likely to be an under-representation based on the absence of coding)

  - Established LTV pathway 392
  - New tracheostomy insertions 81

  - 231 acute admissions
    - Acute admission questionnaires received 152/231
    - Community team questionnaires received 96/166 (not all community teams could be identified)
    - Case notes returned 149/231

  - 161 non-admissions
    - Lead clinician questionnaires received 229/345 (not all lead clinicians could be identified)

  - Tracheostomy insertion questionnaires received 50
Overall assessment of care

- Good practice: 44 (30.6%)
- Room for improvement - clinical: 44 (30.6%)
- Room for improvement - organisational: 10 (6.9%)
- Room for improvement - both clinical and organisational: 37 (25.7%)
- Less than satisfactory: 9 (6.3%)
Key messages (1)

• 1. Service planning and commissioning of integrated services
  • Formalisation of the service planning and commissioning of LTV services through an integrated network of care providers is required.

• 2. Multidisciplinary care
  • 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.
• 3. Emergency healthcare plans
  • Templates for Emergency Healthcare Plans should be developed and standardised for people receiving LTV.

• 4. Discharge planning
  • Active discharge planning should start at the point of an admission

• 5. Transition from child to adult services
  • Transition planning should minimise disruption and prepare for any necessary changes that will occur.
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
e) Where applicable
f) A specialist in tracheostomy care
g) Palliative care/hospice care
h) 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

Recommendation 4
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 the latest by the age of 14 years.
Recommendation 6

Provide a structured training programme and associated resources for long-term ventilation which prepares:

a) People on LTV and parent carers for home care
b) Community providers for routine care
c) Non-specialist clinicians for hospital admissions
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 all people on long-term ventilation have access to age appropriate emergency care by a team with the relevant competencies, regardless of location
Ensure good ventilation care when people on long-term ventilation are admitted to hospital for any reason by:

a) Undertaking a standard clinical and respiratory assessment
b) Undertaking routine vital signs monitoring which includes, as a minimum, respiration rate and oxygen saturation
c) Involving the usual LTV team if not admitted under their care
d) Identifying clinical leadership of ventilation care
Recommendation 11

- 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
Optimise the frequency of clinical review on an individual basis, for those on long-term ventilation who are at an increased risk of admission*

*including people established on LTV < 2 years and those who have had an unplanned admission in the previous 6 months
• Can we identify all children and young people on LTV under the service?
• Is transition planned according to NICE guidance?
• Are joint transition clinics available?
• Are LTV training programmes in place for patients/parent carers and staff?
• Are EHPs reviewed and standardised?
• Are ventilator settings checked regardless of reason for admission
• Are patients at risk of admission, frequently reviewed?
Children and Young People on Long-term Ventilation

Full report, summary and implementation tools are be found at

www.ncepod.org.uk/2020ltv.html