



Balancing the Pressures

A review of the quality of care provided to children and young people aged 0-24 years who were receiving long-term ventilation

Executive summary

Aim

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.

Method

Data were collected from a number of sources to achieve an overall view of the care provided to this group. Data presented in the report highlights: the number of people identified on LTV during the study period; the clinical care provided to a subgroup of people on LTV; the organisation of LTV services; the views of service users, parent carers and health and social care professionals providing the care.

Key messages

The five key messages listed here, agreed as the primary focus for action, have been derived from 12 recommendations (see pages 11-14 and Appendix 1).

1. SERVICE PLANNING AND COMMISSIONING OF INTEGRATED CARE

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.

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. 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.

4. DISCHARGE PLANNING

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.

5. TRANSITION FROM CHILD TO ADULT SERVICES

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.

