

Core guidelines for the discharge home of the child on long term assisted ventilation in the United Kingdom

Elsbeth Jardine, Colin Wallis

The Institute of Child Health and Great Ormond Street Hospital for Children NHS Trust, London WC1N 3JH, UK
E Jardine
C Wallis

For the UK Working Party on Paediatric Long Term Ventilation:

I Barker (Sheffield Children's Hospital), B Boosfeld (Great Ormond Street Hospital for Children NHS Trust), R Bullock (Royal Victoria Infirmary NHS Trust, Newcastle), C Doyle (Royal Liverpool Children's Hospital), S Kerr, R Lane (Great Ormond Street Hospital for Children NHS Trust), K Lucking (North Staffordshire Hospital), J Noyes (University of Salford), M O'Toole (Great Ormond Street Hospital for Children NHS Trust), J Y Paton (Royal Hospital for Sick Children, Glasgow), H Porter (Royal Hospital for Sick Children, Edinburgh), M Samuels (North Staffordshire Hospital), J Shneerson (Papworth Hospital), A Simonds (Royal Brompton Hospital), A Walker (St George's Hospital), T Ward (Chailey Heritage), J W H Watt (Spinal Injuries Unit, Southport), R Yates (Royal Manchester Children's Hospital).

Correspondence to:
Dr C Wallis, Consultant in Paediatric Respiratory Disease, Respiratory Unit, Great Ormond Street Hospital for Children NHS Trust, London WC1N 3JH, UK.

Received 8 January 1998
Returned to authors
31 March 1998
Revised version received
27 April 1998
Accepted for publication
8 May 1998

Abstract

Paediatric home ventilation is a feasible option and can be successful in a wide range of conditions and ages. Advances in ventilator technology and an ethos of optimism for home care has increased the possibilities for discharging chronically ventilated children from intensive care units and acute medical beds. With careful planning the process can succeed, but difficulties often thwart the responsible team, especially when attempting discharge for the first time. These core guidelines aim to assist a smooth, swift and successful transfer. They were developed by a working party of interested professionals spanning a wide range of health care disciplines and represent a synthesis of views accumulated from the experiences of individual teams throughout the UK. Three case scenarios provide further illustrative detail and guidance.

(Thorax 1998;53:762-767)

Keywords: chronic pulmonary disease; home ventilation; discharge planning; paediatric

Mission statement

The child with long term respiratory insufficiency who is stable medically can expect a better quality of life outside the environment of the acute hospital setting. Members of this group are committed to measures which can facilitate this on a national basis.

Introduction

There is a growing cohort of chronically disabled but medically stable children who are dependent on ventilatory assistance to live.¹⁻³ This has arisen in part through advances in ventilator technology, a change in societal expectations of long term disability, and increased survival but incomplete recovery from resuscitation and intensive care.⁴ There are considerable psychological and developmental disadvantages to long term hospital based care.^{5,6} Increasing emphasis is being placed on measures to transfer these children home.⁷ Appropriate medical equipment exists for home care but, in spite of the considerable psychosocial and financial benefits of home mechanical ventilation, the discharge process is often fraught with difficulties. What should be seen as a positive move may emerge as a protracted frustrating experience for all concerned. Disappointingly, some ventilator dependent children remain hospital bound, often in an intensive care environment.⁸

This paper represents a consensus view of a working party of interested professionals from a wide range of health care disciplines.

These core guidelines are intended for those involved in the complex process of discharging a child from an acute care environment to their family home or a suitable alternative, in the safest way and shortest possible time. In most cases a period of patient evaluation at a tertiary hospital will be necessary to complete a comprehensive assessment of needs. There can be no prescriptive discharge process and the guide will need adaptation, based on the needs of the child and family and the availability of resources and local practice.

Definitions

There is a broad range of medical conditions resulting in the need for paediatric long term respiratory support. Common causes include neuromuscular disease, central hypoventilation syndrome, spinal injury, bronchopulmonary dysplasia, and craniofacial abnormality (table 1).^{9,10}

For the purpose of the Working Party the definition of long term ventilation is considered to be "any child who, when medically stable, continues to require a mechanical aid for breathing, after an acknowledged failure to wean, or a slow wean, three months after the institution of ventilation".

Respiratory support varies, according to individual need, from simple mask continuous positive airway pressure (CPAP) during sleep to full 24 hour positive pressure support via tracheostomy. Clearly, the latter presents the greater challenge for planning and needs assessment and care. The bulk of these guidelines pertain to this more demanding exercise although the principles can be extended to cover the child with technically "simpler" needs.

Three case scenarios are provided in the Appendix to illustrate a range of clinical conditions, ventilatory support, professional services, equipment and supplies.

Table 1 Children in the UK requiring long term respiratory support by diagnostic group in 1997*

Diagnostic group	Number in hospital (n=39)	Number at home (n=84)
Neuromuscular disease	10	25
Spinal injury	6	10
Ondine's curse	5	13
Bronchopulmonary dysplasia	5	1
Craniofacial syndromes	0	4
Obstructive sleep apnoea	1	3
Other	12	28

*Data from the UK Paediatric Long Term Ventilation Study (1997).

Goals

The goals of home mechanical ventilation¹¹ are: (1) to enhance quality of life; (2) to sustain and extend life without compromising quality; (3) to improve or sustain physical and psychological function and to enhance growth and development; and (4) to provide cost effective care.

Important central themes run throughout the discharge process:

- the child is a member of the family;
- the family and, where possible, the child should be supported in making informed decisions throughout the discharge process;
- at discharge the responsibility for day to day care will transfer from the hospital to the community health care team and the family.

The decision making process

The option of out of hospital care may be raised by either the medical professionals or the family. The discussions often evolve in informal meetings between medical and nursing staff, a social worker and the child's family. Hospital staff and social services cannot and should not take the place of the family, but should use their expertise to help the family contribute and cope with the process.

A child may be considered suitable for home ventilation if:

(1) The medical condition is stable¹²: this would be a clinical decision and would generally imply:

- the presence of a stable airway;
- stable O₂ requirements (if required), usually less than 40% (this should not exclude terminal care of home ventilated children);
- PCO₂ levels that can be maintained within safe limits on ventilatory equipment that is operable by the family in their home;
- nutritional intake adequate to maintain expected growth and development;
- all other medical conditions are well controlled.

(2) Parents understand the long term prognosis and are willing and capable of meeting the special needs of their child in the home setting.

(3) It is practical to provide the level of support and intervention that the child requires at home.

Not all children benefit from long term ventilation.¹³ If home care is not possible due to family unwillingness, inability to cope, or family desertion then suitable alternative long term arrangements should be sought. It is not appropriate for a child to grow up in a hospital environment.

Discharge team

Discharge of the ventilator dependent child requires a multidisciplinary approach and should be coordinated by one person responsible for liaising with all disciplines. Ideally this individual will have a role in both the hospital and community environment. Some discharge teams consist of two coordinators—a community practitioner responsible for liaising with all members of the community team and a hospital case manager responsible for the hospital team. The latter will often be a nurse from the

ward where the child is based or a social worker experienced in this field.

The team coordinator (case manager) will need to identify all individuals involved in the discharge process as well as the equipment, carers, and respite requirements. The relevant purchasers need to participate from the early planning stage.

Clear documentation of all stages of discharge is essential.

Needs assessment

FUNDING

An immediate approach should be made to the relevant purchaser as soon as the need for long term ventilation is recognised. Frequent communication with the funding source is necessary to ensure that the discharge process runs smoothly.

EQUIPMENT AND SUPPLIES

Equipment chosen for home care should be portable, durable, and simple to use. The aim is *not* to transfer an ITU to the child's home.

An itemised equipment list should be prepared and checked by the team. This should include the make, model, and equipment supplier. The child should be well established on the equipment designated for home use while still in hospital. The equipment list ought to delineate purchased items, leased equipment, and servicing costs. A monthly estimate of disposable supplies and consumables needs to be provided. Details should include revenue consequences, including consumables/servicing costs. Expensive items may be better leased than purchased outright.

A second ventilator is required for any child who is unable to cope for six hours off the ventilator. Alternative power sources in case of mains failure are essential and could be either in battery form or a generator.

Characteristics of equipment that need consideration when making a choice for home use include dimensions, weight, noise of operation, and battery options for travel.

SERVICING AND MAINTENANCE CONTRACT

When selecting equipment for use at home the ongoing costs, ventilator lease/service, and the maintenance contract should be considered. Negotiations with the appropriate company should clarify whether they are responsible for maintenance and replacement during servicing or whether they provide an in-house teaching programme. It is essential that adequate arrangements are in place to deal with equipment breakdown. The patient should receive a replacement ventilator or have their own repaired within an agreed time scale which does not put their continued ventilatory support at risk.

REHABILITATION

Rehabilitation needs consideration when planning the child's long term care. The child with assisted ventilation may have rehabilitation needs extending beyond their respiratory problem. A multidisciplinary focused approach can offer assessments of posture management, provision of related equipment, mobility assessment, and switch communication.

Housing review

The child's home may need to be reviewed by a community based occupational therapist in the presence of the family and, if necessary, in consultation with the environmental health officer. It is advisable that the ventilator dependent child should have his/her own room with adequate space for storage of equipment and stock. The number of power points should be noted (extra wiring and earthing may be needed) and consideration given to fire safety and evacuation routes. Occasionally home modification or re-housing may be necessary prior to discharge.

Home carers

Home carers may be employed to look after the ventilator dependent child but are not always needed. Some families might care for a 24 hour ventilated child alone whereas others find nocturnal CPAP by mask delivery a daunting task.

The level of carer/support required at home will vary with each child and family and is best determined by a comprehensive multidisciplinary needs assessment. Contributing factors may include child related issues such as (a) time dependent on ventilator; (b) dependence (will the child waken or breathe spontaneously if the ventilator fails, becomes disconnected, or their airway obstructs?); (c) means of ventilation; (d) mode of nutrition; (e) whether ambulant or paralysed and the extent of paralysis; and (f) other health issues, or family related issues such as (a) the ability of family to cope safely with the child's care and (b) other demands on the family's time, particularly the presence of other children and work commitments.

Each team of carers should be headed by a qualified paediatric nurse. With the exception of the team leader, carers do not necessarily need a nursing qualification. A well designed comprehensive training programme in the daily management of the individual child makes the training of suitable lay people possible. In the UK home carers (not nurses) may be part funded by the Social Services Department. This requires close liaison between Social Services and the Health Authority who remain responsible for overseeing the training and the ongoing medical care.

The chosen carers may also play a part in the child's emotional and development needs, or assist with home care and sibling management.

It should not be expected that families themselves provide the bulk of additional care required. However, if they prefer to do this, their progress and coping should be monitored. It is the opinion of the authors that, over time, changes to family structure and domestic fortunes may demand re-appraisal of the support provided. The issues of home carers and the long term consequences of home ventilation on families are complex and require further study.

Training programmes and risk management

There are risks associated with home care which are greater than in a high dependency hospital environment. These risks are not eliminated by remaining in hospital or in some

KEY MESSAGES

- Long term mechanical ventilation of children at home is feasible.
- The numbers of children ventilated at home are increasing.
- Early and careful planning leads to a smooth transition to home care.
- Home ventilation has demonstrable psychological, social and economic advantages.

form of institutionalised care. The case manager addresses the need for risk management during the discharge process. A written plan of training and accountability is required and needs to be agreed upon by the hospital, community team, family, and carers. Careful documentation is important because of the medico-legal implications.

FAMILY PREPARATION

Ongoing training of parents and extended family will continue during the child's hospital admission in preparation for discharge home. A separate training programme should be devised for the parents. It would be reasonable to expect, where indicated, competence in tracheostomy care, cardiopulmonary resuscitation, and the routine use of supplies and equipment.

Equipment companies may be approached to provide input to families regarding equipment function and maintenance.

HOME CARERS

A patient specific training package should be devised. The carers need to have a negotiated secondment to the child's hospital to complete the training programme with a short familiarisation course at home. Carers should be deemed competent by the hospital unit and the level of competence should be recorded in the patient's notes.

The responsibility of carer training should never be placed on the parents although the parents will be involved in the training process. Advertising, recruitment and training can be a lengthy process and ought to be initiated early in the discharge planning.

There should be an annual review of cardiopulmonary resuscitation for the carers. Core team meetings need to be held regularly to address problem areas and discuss changing needs. This may include decisions regarding future resuscitation policies and the training of replacement carers.

Communication

Efficient lines of communication need to be established, especially for the child heavily dependent on ventilatory support. The family should have a contact telephone number which is manned 24 hours a day for advice. Patient held records and a full medical summary can be kept in the child's home.

Ideally a telephone should be located in the child's living area. If carers accompany the child outside the home a mobile telephone is

useful. A mobile phone may interfere with electronic equipment and ought not be used in the immediate vicinity of such equipment.

Return to the education system in children of school age

The return to school should be planned whilst the child is still in hospital and in consultation with the hospital education system. Where physical abilities have changed—for example, a patient with a spinal injury—a change of school may be required. If the child is returning to mainstream school, work may need to be done with the child's peers and a gradual return to the education system may be necessary.

The school should be aware of the special needs of the child. The class teacher is a valuable source of information regarding symptoms such as poor concentration, tiredness, and headache which may signify the onset of respiratory illness or inadequate night-time ventilation.

If the child is over two years of age the patient's paediatrician, on behalf of the parents, should write to the local education authority asking it to consider the case for a statement of the child's special educational needs. This is a necessary step in obtaining additional help for the child and enabling them to benefit fully from future education.

Where the child has a team of carers they will accompany the child to school and deal with the medical needs during the school day. If not—for example, a child with a tracheostomy requiring nocturnal ventilation—funding for a carer in the school situation will need to be negotiated.

Emergency procedures

Prior to discharge it is important to notify the emergency services that a ventilator assisted child is resident at that particular address. Services to notify include ambulance, electricity, telephone and the fire service.

Parents ought to inform their car and house insurance companies of the presence of medical equipment, especially oxygen.

Plans for the management of acute exacerbations or changes in medical status must be well established. Channels of communication between the GP, local hospital, and tertiary referral centre need clarification and open access to hospital admission facilitated. Parent held summaries should contain dated and signed comments regarding any limits to resuscitation that have been previously established by the parents and the team and the degree of active management including use of antibiotics and diuretics.

Respite care

Respite care, either in the home or in an alternative setting, can provide assistance to a family fatigued by the isolation, responsibility, and relentlessness of caring for the ventilator dependent child. Plans for respite facilities will need review as the child grows and the families change.

Respite should be in the form that the parents request; the family may wish for staff to accompany them on holiday and not for conventional respite where the child is removed from the family. Others prefer facilities for occasional care. The case manager may consider joint funding for respite between the departments of social services and health. The funding for respite should ideally be costed into the initial care package.

The trial run

Discharge should be approached gradually. Initially the family may need to spend time providing total care for their child in hospital. This is a crucial time for documenting difficulties, concerns, and addressing unexpected issues. The parents and all members of the home care team ought also to have spent time caring for the child in the home setting without hospital back up.

Many teams find a form of trial run at home invaluable. This may consist of a day at home, followed by a trial weekend. The child should use all designated equipment at this time.

Planning the discharge date at a time which suits the family and when back up services are available is essential. When the final discharge day arrives it is best not to choose the Friday evening of a Bank Holiday weekend!

Evolution of ventilatory needs

While the ventilatory needs of some children are likely to remain unchanged—for example, following spinal cord injury—for others ventilatory dependence may increase—for example, in patients with neuromuscular disease. This may require progression to daytime in addition to nocturnal ventilatory use and the consideration of tracheostomy formation in cases with progressive bulbar weakness. These possibilities need to be discussed with carers in advance. Occasionally it may be possible to reduce ventilatory support—for example, following growth in children with craniofacial disorders, tracheobronchomalacia, or bronchopulmonary dysplasia.

The role of the case manager does not end with discharge. Although community support, hospital appointments, and review will have been established prior to final discharge, circumstances change, doctors retire, and patients move.

For the child with an acute intercurrent illness demanding additional treatment, mechanisms for re-admission need to be identified. A secure out of hours contact number and advice line should be established, usually to the hospital ward familiar with the child and the family.

For some children requiring admission to hospital for elective or non-respiratory conditions a general ward may be appropriate, particularly if the community carers continue to have an input to the child. It is recognised, however, that such children may also require intensive care and, due to pressure on such beds, admission may be in a unit remote from their original hospital.

Summary

The prevalence of children dependent on long term ventilatory assistance in the UK is growing. Advances in ventilator technology and an ethos of optimism for home care has increased the possibilities for discharging chronically ventilated children from intensive care units and acute medical beds. With careful planning the process can succeed. These core guidelines aim to assist a smooth, swift, and successful transfer.

Funding: NHS Executive, Research and Development Directorate, Mother and Child Health Programme.

Conflict of interests: none.

- Jardine E, Wallis C. A survey of UK children receiving long-term ventilatory support at home. *Thorax* 1997;52:A23.
- Schreiner MS, Donar ME, Ketterick RG. Pediatric home mechanical ventilation. *Pediatr Clin North Am* 1987;34:47-60.
- Robinson RO. Ventilator dependency in the United Kingdom. *Arch Dis Child* 1990;65:1235-6.

- Fraser J, Henrichson T, Mok Q, *et al.* Prolonged mechanical ventilation as a consequence of acute illness. *Arch Dis Child* 1998;78:253-6.
- Aday LA, Wegner DH. Home care for ventilator-assisted children: implications for the children, their families and health policy. *Children's Health Care* 1988;17:112-20.
- Fields AI, Coble DH, Pollack MM, *et al.* Outcome of home care for technology-dependent children: success of an independent, community based case management model. *Pediatr Pulmonol* 1991;11:310-17.
- Warner J, Norwood S. Psychosocial concerns of the ventilator-dependent child in the pediatric intensive care unit. *AACN Clin Issues Crit Care Nurs* 1991;2:432-45.
- Fraser J, Mok Q, Tasker R. Survey of occupancy of paediatric intensive care units by children who are dependent on ventilators. *BMJ* 1997;315:347-8.
- Gillis J, Tibballs J, McEniery J, *et al.* Ventilator-dependent children. *Med J Aust* 1989;150:10-14.
- Samuels M. Long-term ventilation. *Paediatr Respir Med* 1996;2:24-31.
- Spence A. Home ventilation: how to plan for discharge. *Nurs Stand* 1995;9:38-40.
- American Thoracic Society. Home mechanical ventilation of pediatric patients. *Am Rev Respir Dis* 1990;141:258-9.
- Raphael J, Chevret S, Chastang C, *et al.* Randomised trial of preventative nasal ventilation in Duchenne muscular dystrophy. *Lancet* 1994;343:1600-4.

Appendix: Case scenarios

Case 1: Nocturnal CPAP by nasal mask

Diagnosis:	Crouzon syndrome
Age:	5 year old male
Suitability for ventilation:	Admitted for planned trial of home CPAP. Severe obstructive sleep apnoea diagnosed by polysomnography; no improvement after adenotonsillectomy, nasal CPAP trial successful.
Discharge team:	Tertiary centre paediatrician liaising with local paediatrician. Research registrar trained parents to use CPAP system. Sleep lab staff and ward nurses acting as point of contact. Parents.
Equipment list:	CPAP unit × 1 Headgear Nasal mask Tubing and connectors Filter strips
Time to discharge:	Day 1: need for long term ventilatory support identified Day 2: first discharge planning meeting arranged funding requested parent training commenced Day 4: discharged home
Follow up:	2 × 2 monthly sleep studies followed by six monthly follow up overnight admissions.
Approximate costs (excluding hospital and follow up costs):	Capital costs £500 Consumable costs £200 per annum Service costs £40 per annum Staffing costs £0

Case 2: Nocturnal ventilation by nasal mask

Diagnosis:	Congenital myopathy
Age:	8 year old female
Suitability for ventilation:	Admitted for elective introduction to home ventilation. Marked hypoventilation recorded on polysomnography - commenced on nocturnal BiPAP with correction of hypoventilation shown by repeat sleep study.
Discharge team:	Tertiary centre paediatrician liaising with local paediatrician, GP, health visitor, local physiotherapist and school. Home care nurse/technician dealing with training of parents. Parents and child.
Equipment list:	Bi-level ventilatory support machine × 1 Nasal mask Headgear Ventilator tubing and spare circuitry Disposable filters Easy to use instruction booklet for parents and local health care team
Time to discharge:	Day 1: need for long term ventilation identified Day 2: first discharge planning meeting arranged funding requested parent training commenced Day 7: discharged home
Follow up:	2-4 weeks after discharge, then alternate two monthly appointments with local paediatrician and tertiary centre.
Approximate costs (excluding hospital and follow up costs):	Capital costs £4000 (average life span 5 years) Consumable costs £270 per annum Service costs £400 Staffing costs £0

Case 3: 24 hour ventilation via tracheostomy

Diagnosis:	High spinal injury, motor vehicle accident
Age:	3 year old male
Suitability for ventilation:	Fractured cervical vertebrae C2, with subluxation C2 on C3. Cervical cord transection with quadriplegia. No other medical problems.
Discharge team:	<p><i>Hospital</i></p> <p>Care co-ordinator liaising with purchaser/fundholders, identifies appropriate community team personnel, co-ordinates discharge planning meetings and overall discharge plan.</p> <p>Paediatric consultant responsible for all clinical management.</p> <p>Named nurse gives daily input re progress, involved in the assessment of suitable equipment, participates in parental and carers' education package, involved in documentation of care plan, acts as direct parental and child advocate</p> <p>Psychiatry occupational therapist - play therapy and post trauma</p> <p>General occupational therapist - identification of appropriate development and communication equipment, liaison with community OT.</p> <p>Psychologist supporting family and child</p> <p>Social worker - financial assessment re benefits, liaising with appropriate community social work team re housing grant applications</p> <p><i>Community</i></p> <p>Community service manager responsible for recruitment of home care team and funding of care package (equipment and home care team) via Trust/Health Board</p> <p>Social work, OT - implementation of home assessment recommendations</p> <p>Community paediatrician - to promote home care package, special needs statementing, overview of ongoing needs</p> <p>GP - provision of general medical backup post discharge</p> <p>District nurse manager - involved in the recruitment process, co-ordinates ordering of supplies</p> <p>Home care services - provision of home help service</p> <p>Health visitor - as family advocate in community setting, overview of health and development of child and of family dynamics.</p>
Equipment list:	<p>Pressure limiting ventilators × 2</p> <p>Ventilator alarm</p> <p>Battery × 2</p> <p>Ventilator tubing and spare circuitry</p> <p>Humidifier × 2</p> <p>Pulse oximeter</p> <p>Suction machine</p> <p>Resuscitator</p>
Time to discharge:	<p>Day 1: spinal injury</p> <p>Day 85: need for long term ventilation identified</p> <p>parent training commenced</p> <p>Day 121: first discharge planning meeting</p> <p>funding requested</p> <p>Day 193: funding agreed</p> <p>Day 227: nurse recruitment began</p> <p>Day 259: nurse training programme started</p> <p>Day 289: discharged home (following a trial period at home of 4 weeks)</p>
Follow up:	<p>Protocols for referral to hospital devised - community team aware of the same</p> <p>3 monthly review by hospital team.</p> <p>General health and development reviewed and managed by local/community team</p> <p>Care co-ordinator and named nurse remain as links from tertiary hospital for any issues arising.</p>
Approximate costs (excluding hospital and follow up costs)	<p>Capital costs £18 000</p> <p>Consumable costs £7000 per annum</p> <p>Service costs £260 per annum (emergency call out charge Mon-Sat £67 per hour, Sun £88 per hour)</p> <p>Staffing costs £100 000 per annum</p> <p>Additional equipment:</p> <ul style="list-style-type: none"> ● snug seat and future powered wheel chair provided by mobility centre ● elevating bed and hoist provided direct by community trust ● physiotherapy equipment (splints, boots, spinal jacket, collars, tilt table), initial expenditure £2200, but many items are on ongoing cost ● communication tools supplied by the education department ● required re-housing: adaptations initially funded by parents with reimbursement pending from the local authority and accident liability claim