Analysis of home support and ventilator malfunction in 1211 ventilator dependent patients

M. Chatwin\textsuperscript{1}, S.Heather\textsuperscript{1}, A.Hanak\textsuperscript{1}, M.I.Polkey\textsuperscript{1}, A.K.Simonds\textsuperscript{1}.

\textsuperscript{1} Academic and clinical department of sleep and breathing, Royal Brompton Hospital, Sydney Street, London, UK

**Correspondence to**

Dr Michelle Chatwin  
Sleep and Ventilation Unit,  
Royal Brompton Hospital,  
Sydney Street, London, SW3 6NP  
United Kingdom  
Fax +44 20 7351 8911  
Tel +44 20 7351 8027  
Email m.chatwin@rbht.nhs.uk

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Abstract

Risk management is an important aspect of home ventilation (HV). We examined the nature of calls to a home support helpline, to identify patient/equipment problems and strategies to minimise risk for patients, healthcare teams and manufacturers.

Methods: From 1211 adult & paediatric patients with neuromuscular disease, COPD or chest wall disease receiving HV, all calls to a dedicated respiratory support telephone hotline between 1/1/06 and 30/6/06 were analysed.

Results: 1199 patients received non-invasive ventilation (NIV), 12 tracheostomy ventilation: 149 had 2 ventilators for 24 hour ventilator dependency. There was a mean of 528 daytime calls/month and 14/month calls at night. Following 188 calls a home visit was performed; these identified a technical problem which was solved in the patient’s home in 64% or required replacement / parts in 22%. From 25 calls in which no mechanical fault was identified, 13 patients were unwell or required hospital admission.

Conclusion: Patients using HV have a substantial requirement for assistance, with most technical problems being resolved simply. Where no fault can be found during an equipment check, the patient him/herself may be unwell and should receive early clinical evaluation. The patient may have mistaken clinical deterioration for an equipment problem.
Introduction

The topic of ventilator breakdown and adverse events in patients receiving home ventilation (HV) has received little attention which is surprising considering HV is a rapid growth area and there an increasing focus on risk management. Srinivasan et al., [1] examined ventilator-related problems in a group of US patients, the majority (76%) of whom were receiving tracheostomy ventilation. They reported 189 ventilator problems in 150 HV users over a one year period. Thirty nine percent were due to defective ventilatory equipment or mechanical failure, in 30% equipment was improperly used by carers, and 13% were due to improper care or damage to equipment. Three per cent occurred due to a change in the patient’s condition that required a change in ventilator setting and in 16% of reported events no problem with the equipment or ventilator was found. To resolve the problem the ventilator was replaced in 44% of cases. Interestingly 14% of these replacements were primarily to reassure the patient and carer, as no fault was identified. Hospitalisation was only required in 1% of the reports. It should be noted that this predominantly invasively ventilated population differs considerably from groups receiving HV in Europe where non-invasive ventilation (NIV) predominates [2].

There are however anecdotal reports of serious problems. Lechtzin [3] described a US patient with motor neurone disease/amyotrophic lateral sclerosis who had initially responded well to NIV, but as he became more ventilator dependent there was no associated progressive care plan. He died suddenly at home. The ventilator alarm log showed power failure was the cause, with no evidence of ventilator malfunction. No battery back-up was available. A similar case of a ventilator-dependent patient dying during a power cut has been reported in the UK [4].

The landmark Eurovent [2] study investigated the provision of HV across the European Union. As part of this survey Farre et al., [5] examined the quality control of home mechanical ventilation equipment and care packages. Considerable differences in patterns of care were identified between countries. Some hospital teams continued to supervise care in the home, in other countries there were dedicated regional home care organisations, or commercial
home care providers were employed. Regular servicing was carried out by external companies in 62% of centres. Communication between hospital and home care providers was variable. Seventy two percent of hospitals reported being informed of equipment problems, but only 61% of hospitals were always informed of major incidents. Unlike reporting of adverse reactions to drugs, there was also a lack of knowledge about where to report adverse events that had occurred with ventilatory equipment.

From a medico-legal perspective, the care and maintenance of ventilatory equipment in the home is normally the responsibility of the prescriber unless that role has clearly been handed over to another party. As the hospital usually retains clinical responsibility for the patient, communication between teams is vital. Lloyd Owen et al., [2] demonstrated that patterns of quality control in HV in Europe vary, at least in part as there are no well established guidelines. The first aim of this study was to analyse ventilator malfunction in the patient’s home. The second aim was to assess the calls received by a telephone support line from a large mixed, adult and paediatric population, provided with HV by a regional centre.
Methods

Our centre has provided HV since 1987 - as patient numbers have grown so has the service to support ventilator dependent individuals in hospital and at home. Patients are usually referred to our centre via their general practitioner (GP) or via a consultant from their local hospital. The service provided is part of the national health service (NHS) meaning it is free and open to anyone. Initially the service consisted of one technician and one respiratory consultant physician. During the current evaluation the respiratory support team consisted of 2 respiratory consultant physicians’, 2 trainee doctors, 5 respiratory support allied health professionals (including 1 clinical nurse specialist) and 1 administrative coordinator. Working hours are 9.00-17.00 Monday to Friday; any calls or support outside these hours is viewed as an on-call/emergency service. After 17.00 an emergency telephone line is answered by the NIV ward nursing staff (rotating mix of 4 nurses) who are all trained in NIV problem. All telephone calls are charged at a local rate.

At initiation of HV all patients are reviewed by the respiratory consultant physician who confirms indications for treatment and determines the ventilatory regime. Patients using NIV are fitted with a mask interface and initially acclimatised to the ventilator at appropriate settings during the day [6]. We have previously reported that inpatient initiation of HV takes a mean ± SD of 3.8 (1.0) days and outpatient between one and two sessions [7]. The ventilator is set up so that the pressure or tidal volume ensures a comfortable but adequate thoracic expansion and reduction in accessory muscle activity. Settings are further titrated after overnight monitoring of arterial oxygen saturation and transcutaneous CO₂ level and mask fit reviewed. All our HV patients undergo a educational programme to minimise the risk of adverse events as previously reported [8]. This is to ensure patients / carers are competent in assembling the circuitry and are able to fit the mask and headgear effectively. Pre-discharge patients or the main career are assessed the following key competency areas which are covered in the educational programme (Box 1). Patients are discharged home with education packs; these included written material developed in the unit. This material was personalised to the individual to include mask and ventilator information and includes the patient’s degree of urgency (level of priority) if equipment failure occurs and provides contact telephone
number and information about our external service and maintenance company. Refresher education is provided at clinic visits and during inpatient readmissions.

At our centre we use an external service and maintenance company (Smiths Medical, Watford, UK); this company services all ventilators according to manufacturer’s guidance (usually annually) in the patients’ home. Patients are classified as a one night degree of urgency (DOU) (able to function for part or 1 night off ventilation), two DOU (able to function for 2 nights without ventilatory support) and as three DOU in order for the service and maintenance company to prioritise their call outs. Once a fault has been identified the external service and maintenance company are called. The external service and maintenance company immediately call the patient to acknowledge they have been notified and arrange the repair the ventilator in the patient’s home within the patients DOU. The external service and maintenance company technicians aim to fix the equipment or replace it with an identical ventilator model at prescribed settings, if the problem cannot be resolved. If there are any medical matters arising the technicians from the external service and maintenance company will call the team at the Brompton explaining the situation and advice is given to the patient. If it is the case equipment is required they will also notify the Brompton team and this will be sent out. At the end of each month summary information is reported to us, this includes the type of ventilators that are breaking down and a summary of each visit.

Between the start of January 2006 and the end of June 2006 demographic data was collected from our hospital patient database. This is an ongoing service and patients are registered on the database when they are discharged from hospital with HV. Over the 6 month period we were responsible for providing home ventilation to 1211 adult and paediatric patients; diagnosis, age of commencement of HV, whether the patients were receiving T-IPPV or NIV, how many ventilators were provided per patient, and level of ventilator dependency are recorded.

We prospectively manually entered into a database the number of telephone helpline calls we received within a six month period from our 1211 patients. This was sub divided into calls
received between 09.00 to 17.00 Monday to Friday, the calls were taken by 4 respiratory support allied health professionals who are trained in HV, three having a physiotherapy background, these individuals are dedicated to the HMV programme. The respiratory support allied health professionals triaged the calls and notified the respiratory physicians if they suspected a medical problem and this was followed up by the doctors, if an equipment problem was suspected the external service and maintenance company was contacted. The other group we evaluated were calls to our on call/emergency telephone helpline, which was also recorded into a data base. The emergency helpline number is answered by nursing staff on a ward dedicated to HV. If the nursing staff was unable to resolve or triage the problem, there was back-up advice available from a dedicated NIV respiratory support allied health professional on call (See Figure 1). We evaluated details of the reports to the emergency help line number from all patients. We also recorded information during the six month period from the external service and maintenance company on nature of the emergency visits for ventilator breakdown, the faults identified and remedial measures taken.

All patients who are stable after initiation on HMV are seen after three months in the Outpatient clinic. Depending on the severity and disease progression they are then seen between three and nine monthly. As our HV population live in widely dispersed areas of England and Wales our medical team carry out few home visits (<2/month). After each clinic visit or hospital admission the GP and referring centre receive a letter documenting treatment and contact information. If there is a reason why this information needs to be communicated urgently the letter is faxed to the centre and one of the doctors on the team will telephone the local physician. All home visits relating to this study have been carried out by our external service and maintenance company’s technicians. The hospital based medical team liaises with the patients’ GP after each clinic visit by letter and if the hospital based team has identified a potential deterioration in the patients condition they will request that the GP carries out a home visit to assess the situation.
Results

Between 1/1/06 and 30/6/06 we were responsible for 1211 adult and paediatric patients (642 M and 589 F) receiving HV. The total working hours team to patient ration is 1:121 patients. Individuals had been using HV from 3 months to more than 15 years. Mean age at treatment was 46 ± 21 years old, age range 3 months old to 87 years old. Diagnoses for the patient population by age groups are shown in Figure 2. Our respiratory support team (4 respiratory support allied health professionals and 1 co-ordinator) received an average of 528 daytime calls per month lasting a mean ± SD of 4.5 ± 6.9 minutes. 63% of calls were received in the morning and 37% in the afternoon. Only 3% of repeat calls received in daytime working ours were about the same query. One percent of 1211 patients called outside working hours. 14 calls per month were to the oncall/emergency telephone help line.

Level of ventilator dependency was determined by the patients/medical team at time of initiation of NIV and reassessed if the medical condition changed. 17% of patients were classified as a one DOU, 33% two DOU and 50% as three DOU. 149 / 1211 (12.3%) required 2 ventilators for 24 hour or near 24 hour ventilator dependency. As our NIV service began over 20 years ago, our patients have ventilators made by a variety of manufacturers. Fifty percent used bi-level pressure preset ventilators. Forty eight percent received single level pressure preset ventilators and 2% use volume ventilators. Thirty two percent of patients had battery back up and 10% of patients had supplemental long term oxygen therapy.

We examined in detail the 86 calls that were made to the on call/emergency telephone support line. The age of the patients was 53 years old with a range of the individuals effected being 3 – 90 years old. The amount of calls were similar between the diagnosis groups when taking into the account of the total amount of patients (34% neuromuscular disease (NMD) 2 of these had motor neurone disease, 39% chronic obstructive pulmonary disease (COPD), 16% obesity, 5% chest wall disease (CWD), 3% upper airway problems (tracheomalacia and cranio facial abnormalities, cerebral palsy and trisomy 21) and 8% other. Nineteen percent of the calls were from patients with a one night DOU, 10% with a two night DOU and 72% with a three night DOU. Half (43/86) of the calls were to report issues with the ventilator, but despite
the education programme the remainder of calls were non urgent and did not fit the criteria for use of the emergency number e.g. they were routine queries or requests for interfaces. Analysis of the nature of these calls is given in Table 1. Seventy five percent of calls related to suspected technical problems, e.g. alarms and ventilator not working were made because the patient / carer suspected there was a problem with the ventilator, and 25% of patients/carers telephoned as the ventilator had identified a problem, triggering an alarm. 16% of the total number of calls were about a problem previously reported.

In the six month period our external service and maintenance company carried out a total of 188 home visits because of ventilator or associated equipment-related problems that could not be diagnosed or solved by simple telephone advice. 41 of the 188 home visits were requested after being reported to the emergency/on call line. 32% of home visits were to NMD patients, 32% COPD, 14% CWD, 9% obesity and 13% other. The mean age of this patient group was 52 (range 1-82) years. No home visits were required by patients using tracheostomy-ventilation. Despite regular equipment servicing programme, in these 188 patients there was a technical problem with the equipment which was solved in the patients home in 64% of cases or required replacement/parts in 22%. Problems identified by the service and maintenance company in the patient's home are shown in Table 2. All telephone calls were screened by the respiratory support allied health professionals team to ensure the problem was likely to be equipment malfunction and not a simple error such as forgetting to plug in equipment or disconnection of circuit.

In 13% of home visits no technical problem with the ventilator or circuitry was identified despite a detailed performance check. Review of the circumstances of these episodes showed that in in all 25 visits in which no equipment fault was found. In these 32% involved COPD, 28% NMD, 8% obesity and 8 % bronchectasis patients. There DOU was I night 28%, 2 nights 4%, 3 nights 68%. 13/25 patients were unwell at home and/or required a hospital admission; 2 patients died within 1 month of identification of ‘no fault’. Both these patients died were as a result of an acute exacerbation of COPD. Of the patients that were unwell at identification of ‘no fault’ all had respiratory tract infections except ione NMD patient who
became more ventilatory dependent due to deterioration in respiratory muscle weakness. There was no association between acute infection as cause of reported problem and level of ventilator dependency highest ventilator dependency (1 night 15% and 3 night 85%).

Analysis of ventilator breakdown rates adjusted for total number of ventilators in our service showed there was an increased malfunction rate in ventilators that had been in service for more than 8 years for example the Respironics PLV 102 life care (although no ventilator was used beyond manufacturers’ recommendations) and in ventilator models newly on the market. Importantly there was also an increased equipment failure rate in highly ventilator dependent patients (use > 16 hours/day), suggesting that failures are related to total hours of use. There was on average an 8% failure rate per manufacturer when the old and very new ventilators in are service are included in the breakdown. The commonest causes of ventilator malfunction in our group of patients were motor blower or bellows failure, and circuit board ceasing to function. A large amount of alarm problems were identified by external service and maintenance company were as a consequence of water in a pressure line. This problem was resolved in some models by inserting a small filter.
**Discussion**

The main finding of the present study is that patients have a substantial requirement for assistance with their ventilators at home. From our data we expect each patient to make 5.5 telephone calls to the hospital per year and 3% of these calls will be in the evenings and at weekends/public holidays. The majority (78%) of home visits from the external service and maintenance company were as a result of day time calls. From a risk management viewpoint no patient whose equipment required repair or replacement suffered adversely or required admission. However we have identified a group of HV users who report a ventilator related problem but no fault can be found during an equipment check conducted by an experienced engineer. Here patient him/herself is likely to be unwell and we would strongly recommend early clinical re-evaluation after calls where no fault is identified. In this situation it is likely that the patient has misinterpreted clinical deterioration for an equipment problem, or it is simply that due to changing pathophysiology the ventilator settings no longer meet the patient’s ventilator requirements.

In 2001 our centre had a similar diagnostic casemix as the Eurovent study - approximately a third had neuromuscular disease, a third chest wall disease and the remaining third had COPD [2]. By 2006 the distribution receiving HV was neuromuscular disease 33%, 16% chest wall disease, and 15% had COPD but the proportion with obesity hypoventilation syndrome and other airways disease (bronchiectasis, cystic fibrosis) had increased. It is likely that there are fewer patients presenting with chest wall disease as a late effect of radical surgery for tuberculosis following the introduction antituberculous chemotherapy [9]. Our practice is in line with other countries in Europe regarding servicing and maintenance of our ventilatory equipment, as it is managed by an external company [5].

We identified two areas that contributed to ventilator breakdown rate: increased total hours of ventilator use, and models which were new to the market. It is not surprising if ventilators are used for longer periods and are older that the parts will be need to be replaced earlier in these
patients. However, manufacturers need to be aware that when they develop new ventilators there may be problems which are not identified on pre-market testing. We have not specified the manufacturer or model as we feed back to the company directly and subsequently to have modified the device and have resolved the problem. One solution for increased ventilator failure rates in new machines may be for the company to bench test equipment for longer periods, or to provide spare units in anticipation of problems. Reporting to a central body on ventilator problems with certain devices is essential and these data should be collated and disseminated as part of the medical devices directive. In the UK adverse events are be reported to the Medicines and Healthcare products Regulatory Agency (MHRA- www.mca.gov.uk). Manufacturers also need to ensure that alarms work appropriately. In our study only 75% of calls regarding equipment dysfunction were instigated because the patient or carer detecting underperformance and not because of an alarm that was activated. Our data supports work of Farre et al., [10] who identified ventilator alarms were not always available or set appropriately in patients using non invasive ventilation.

Assessment of ventilator performance at home is required for patient safety; but patients also need to be re-evaluated to ensure ventilator settings remain optimal. Farre et al., [11] reported that the performance of a home mechanical ventilator in patients’ home can be vary considerably. They found significant differences between actual, set and prescribed tidal volumes and respiratory rate. In order to reduce these discrepancies they recommended that ventilators are serviced regularly to ensure quality control. Our centre adheres to this recommendation however, there were still patients in whom additional home visits were required to assess the performance of the ventilator. We found mechanical ventilator failure rate to be relatively low accounting for 28% of call outs to the home. This is similar to the ventilator failure rate reported by Srinivasan et al., [1] However a more frequent problem is the patient or carer not recognising that tubing or masks are damaged, despite a competency based education programme. Plant et al., [12] showed that it is more cost effective to set up NIV on a single ward that regularly carries out NIV setups rather than on different wards in the same hospital. They felt that this was attributable to training issues and retention of knowledge of staff. Equally inconsistent patient education may cause an undue number of
non emergency call outs so that educational information needs to be regularly repeated and competencies reassessed.

In 13% of the visits no fault with the equipment was found. In a previous study [1] that identified ‘no fault’ with the ventilator, 2 patients were hospitalised due to a change in their condition. Of our sub group of 25 patients that reported ventilator problems but none was identified, half were unwell either at home or in hospital and two died with in a month. Patients may misinterpret a change in their health e.g. an infective exacerbation, sputum retention, bronchospasm, or pulmonary oedema as the ventilator not working properly. Although they may well benefit from changes in the ventilator settings to deal with the pathophysiological change e.g. increased airways resistance, or reduced lung compliance, the underlying problem is with the patient, not the ventilator equipment and further treatment may be urgently required. If these patients are admitted to other hospital not familiar with ventilator use, health care professionals may also be quick to attribute the problem to equipment failure, and less likely to realise that there has been a primary change in the patient’s health requiring active management including secondary changes in ventilator settings. HV users who repeatedly call a telesupport line should not be labelled as ‘difficult’ or overanxious if no technical malfunction can be found with their ventilator, circuitry or interface. These individuals need to have either have an emergency clinic appointment and clinical assessment, or home visit by the GP or medical team to prevent a potential adverse event as a consequence of deterioration in health. Education should be provided to new trainees about patients who call regularly so the most appropriate advice can be given, and to patients themselves to help them identify warning symptoms.

With the growing provision of home mechanical ventilation, service and maintenance is often carried out by external companies. Unlike some units, [5] our centre receives regular feedback about ventilator performance and changes in settings as well as more detailed information about the patient. We strongly advocate centres have regular feedback about their patients to allow them to monitor and review them from afar, and identify new equipment problems. With the development of new technology [13] and improved telemedicine options [14, 15] even in very vulnerable patients [16], it is possible to download symptom scores,
arterial oxygen saturation levels and ventilator performance details on tidal volume, pressure and leaks daily [14, 15]. Indeed there are pilot studies in progress with some ventilators which are able to monitor pulmonary mechanics and adapt settings accordingly. If these advances are shown to be valid and cost effective, the logical next step in risk management is to identify those HV patients in which this extra information may aid care, rather than extend extensive monitoring support indiscriminately to all HV recipients.

Limitations

The limitations of this study includes that we do not record the amount of scheduled calls made to patients. Our centre does not provide a routine home visits from doctors or the hospital based team due to the wide geographical area that we cover. If it is identified a patient needs a medical review we will ask the GP to review or arrange a home visit or and appointment at the GP surgery to assess the patient. Despite immediate communication from the hospital to the community teams some local professionals feel less able to cope with medical problems in ventilator dependent patients, as they are anxieties about NIV/changing settings etc. The availability of a team member who can visit patients and deliver support and education to the community teams would improve the community support that the hospital provides. Out of the 86 calls to the on call emergency helpline number only 7 patients called twice, indicating that the potential problem can be remedied effectively. Only 1% of our population had motor neurone disease (MND). We attribute this small number to the poor prognosis of this disease compared to other neuromuscular diseases, and lack of neurology referrals, but these are increasing. Other centres may have a greater number of patients with MND and all these patients will need an evolving care plan and a greater amount of support compared to a more slowly progressive NMD. The upper airway disease group includes 28% who have failed auto-titrating CPAP devices and progressed to NIV. All paediatric and young adult patients in the upper airway group had tracheomalacia, trisomy 21, cerebral palsy or cranio-facial abnormalities and because of the common problem of upper airway collapse they have been grouped together.
All members of staff are highly trained in HV and had experience of problem solving over a number of years; this skill mix might not be available in newly developed units. Despite the limitations of this study we feel our experience may be relevant to other centres providing HV and those planning a service.

In conclusion, there is a significant workload associated with supporting home ventilation patients. Despite patients/carers receiving competency training before discharge, regular re-education is required and non-urgent other calls may be reduced by a more flexible problem-solving approach. Importantly, reports in which no technical fault is found may indicate deteriorating health in the patient and these individuals require close clinical re-evaluation.
References


Acknowledgements
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Box 1

1- Basic information includes; why the patient requires non-invasive ventilation, the degree of ventilator dependency (how long they can safely manage without their ventilator if it malfunctions), the purpose of alarms, servicing and maintenance plans, who to contact if the ventilator breaks down and how to order spares for the equipment (masks, tubing, filters etc).

2- Practical aspects; Patients must be able to turn the ventilator on and off, put the mask on and off and assemble mask and headgear after washing, also demonstrate that they can change the circuit, and lock and unlock the ventilator if they need to change settings with instructions over the phone.

3- Technical information; we also ensure each patient knows the precise model of their masks and ventilator and have received standard information including the manufacturers handbook and the correct telephone numbers to re-order spares, and the emergency help line number for ventilator breakdown or problems.

4- Additional more complex competency training is provided for patients with a tracheostomy and their carers/families. This includes training in tracheostomy tube changing and care, use of suction machines, heated humidification and problem-solving e.g. dealing with blocked or displaced tubes which is beyond the scope of this paper. T-IPPV patients frequently have a high level of ventilator dependency therefore require back-up ventilators, suction machines etc.
<table>
<thead>
<tr>
<th>Description</th>
<th>Out of hours calls (n=86)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Equipment required (tubing, filters, mask spares)</td>
<td>23</td>
</tr>
<tr>
<td>Technical issue (included alarming, not reaching pressure, noisy)</td>
<td>22</td>
</tr>
<tr>
<td>Ventilator not working</td>
<td>19</td>
</tr>
<tr>
<td>Advice: non emergency</td>
<td>13</td>
</tr>
<tr>
<td>Advice about continuous positive airways pressure (CPAP)</td>
<td>5</td>
</tr>
<tr>
<td>Advice: emergency</td>
<td>2</td>
</tr>
<tr>
<td>Battery not working</td>
<td>1</td>
</tr>
<tr>
<td>Request for Servicing</td>
<td>1</td>
</tr>
</tbody>
</table>

This table provides information about the out of hours calls to the emergency help line. There were sub classified in to equipment required, this is where the patient ought to have called to request replacement consumables. Technical issues were the ventilator could be turned on but there were reports of it being noisy, an alarm going that the patient could not resolve the problem with telephone support and the ventilator not giving the same size breath as the patient felt was normal for them. The ventilator not working meant that despite the power being connected the ventilator did not start up. An example of no emergency advice was the patient complained of mouth dryness.
### Table 2
Reason for emergency visit over the 6 month period

<table>
<thead>
<tr>
<th>Reason for Visit</th>
<th>Number of home visits (n=188)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ventilator not working</td>
<td>52</td>
</tr>
<tr>
<td>Technical issue (alarming, not reaching pressure, noisy)</td>
<td>43</td>
</tr>
<tr>
<td>Equipment required (tubing, filters, mask spares)</td>
<td>39</td>
</tr>
<tr>
<td><strong>No fault</strong></td>
<td>25</td>
</tr>
<tr>
<td>Circuit fitted incorrectly</td>
<td>9</td>
</tr>
<tr>
<td>Hospital requested exchange</td>
<td>9</td>
</tr>
<tr>
<td>Patient changed settings by mistake</td>
<td>8</td>
</tr>
<tr>
<td>Patient did not like replacement vent</td>
<td>2</td>
</tr>
<tr>
<td>Set up of ventilator at home</td>
<td>1</td>
</tr>
</tbody>
</table>
Legends

Figure 1

This Figure shows the organisation of staff involved in answering the emergency phone line (black box) and the dedicated line for replacement parts or technical advice (dark grey box) along with the number of staff involved (n=number of staff). Out of hour’s organisation is shown in the top half of the Figure and working hours in the bottom half of the Figure.

Figure 2

This Figure shows the number of patients aged 1-16, 17-30, 31-50, 71-70 and 70+ years old. Each age group has the number of patients per diagnosis. Neuromuscular disease (NMD) including motor neurone disease, central hypoventilation syndrome (CHS), obesity hypoventilation syndrome (obesity), chest wall disease (CWD), upper airway (UA) (tracheomalacia, cranio facial abnormality, cerebral palsy, trisomy 21 and 28% intolerant of auto titrating continuous positive airway pressure), chronic obstructive pulmonary disease (COPD), bronchiectasis, other (other diagnosis including lung disease e.g. pulmonary fibrosis).