

Final Report.

***“Breathe-on UK”* Patient reported outcome measures study (PROMS) of children on long term ventilation (LTV).**

August 2012.

Introduction.

Changes in the ways in which children and young people with a wide range of complex disorders are cared for has meant that, over the past decade there has been a very large increase in the numbers of children and young people receiving long term help with their breathing by means of a ventilator (1,2).

Definition.

A child receiving long term ventilation is defined ^{1,2,3} as:

Any child below the age of 18 years who is medically stable and requires mechanical assistance with breathing (either invasively by a tracheostomy or by non-invasive mask interface) for all or part of the 24 hour day for a period of more than 12 weeks.

Some infants who are born very early (particularly those born before 28 weeks gestation) and some infants with complex conditions affecting the heart or lungs will require ventilatory support for a prolonged period, but will be weaned from the ventilator before discharge from hospital, and will not be expected to require further ventilatory support. These infants were not therefore included in the present study, even if they required ventilator support for more than 12 weeks.

Aims.

The aim of this study was to collect information on the nature and quality of the care and support offered to these children and young people and their families, in the period during which ventilator support was initiated, and in the subsequent months and years during which it was continued – either in hospital or (increasingly commonly) at home.

The study aimed to collect information from as many families of children receiving long term ventilatory support in England as possible.

Methods.

Inclusion criteria.

All families of children beyond the neonatal period (1 month from birth) who have been receiving ventilator support for part or all of the day for a period of at least three months, and whose condition is stable enough for delivery of the ventilatory support at home or in a non-intensive care facility to be considered appropriate. We aimed to include all such children who commenced long term ventilation before their 18th birthday, even if the child is now aged over 18years.

Information collected.

We aimed to collect information on the perceptions and assessments by parents and children of the decision-making processes leading to the establishment of long term ventilation (LTV), the processes involved in deciding where this should be provided (e.g. home or hospital), and the quality and content of the teaching /training and support of parents before and after discharge from hospital or the move to a facility in which LTV is to be continued.

The information was collected primarily from parents and family members of children receiving LTV, with an emphasis on using the parents' perceptions of the quality of provision of care and support to develop guidance on appropriate and ultimately auditable standards for the provision of such care.

The questionnaire was developed with input from a broad range of professionals involved in the provision of LTV services (including paediatricians, intensivists, hospital and community based nurses), plus several families of children with a range of underlying medical conditions who were receiving LTV.

The questionnaire included questions covering three main areas:

1. The nature of the condition in the child giving rise to the need for LTV, and basic demographic information about the child and family.
2. The processes from the time of recognition of the possible need for LTV until the establishment (in hospital, other institution or at home) of stable LTV.
3. The support provided to the family and their perceptions of the quality of care provided after establishment of stable LTV.

In each section, in addition to being asked factual questions about their experience, the parents were asked about their good and bad experiences and views, and about ways in which the service could be improved.

The identification of children on LTV

Breathe-on UK already has contact with many families of children on LTV in many parts of England, and has established a list of paediatricians, intensivists and care providers involved in the provision of care to children on LTV. By using these existing contact lists, plus using relevant professional organisations* to identify other relevant professionals we hoped to identify all those responsible for continuing provision of care to such children and their families. The professionals were asked to send information on this study to all families of children receiving LTV under their care, and to invite them to contribute to the study.

Professionals were also asked to send a form to “Breathe-on UK” giving information on the number of families to whom they had sent the request to participate, but no personal identifiers or information about families were sought from professionals.

(* Professional organisations included: PICANET, BAPM, BPRS, the LTV working party)

Approach to Families.

Families were invited to complete either an on-line questionnaire or to complete and return a paper version of the questionnaire. For those with difficulties completing a written questionnaire the opportunity was offered to complete it over the phone with an experienced paediatric nurse.

The on-line questionnaire was open to families to complete from March 30th to June 27th 2011.

Although personal identifier information (name, date of birth, and home address of the child) was requested from the person completing the on-line questionnaire in the first page to minimise the risk of duplication of entries, this information was not included in the database, and, once data on geographical distribution of families and ages of children had been calculated from the information given and entered into the database the personal identifier information was deleted unless the person completing the questionnaire had given express permission for “Breathe-on UK” to retain the information and make future contact*. No personal identifier information was included in the study database at any time. Parents who completed the form but did not answer the question on whether the personal information could be retained were contacted once by mail or email to obtain an answer to this question. Personal identifiers on all those who did not give permission for this information to be retained, or who failed to answer the single further communication were deleted after 2 weeks.

*[*This will be by mail or email for the purposes of providing information on the activities of “Breathe-on” or to provide relevant information for families of children on LTV. The information will not in any circumstances be passed on to any other person or organisation].*

The database thus contained only anonymised data.

Results

1. Data collection process

Numbers of questionnaires completed.

From the forms returned to “Breathe-on UK” by professionals, approximately 450 families were contacted by their health care professionals, but more may have been informed of the study by other families.

A total of 147 questionnaires were completed, approximately 33% of those to whom invitations had been sent.

Of the families who completed the questionnaire, 132 (89.8%) gave explicit consent for “Breathe-on UK” to make further contact.

Three families indicated that they did not wish to have further contact, and a further 12 families did not answer this question or reply to the enquiry as to whether their information could be kept. The personal identifiers for all 15 families were therefore deleted although their responses to the questionnaire are included in the analysis.

Completeness of Response.

Certain questions that sought factual information about the child,, the type of LTV delivered, events around the time of commencing LTV, and subsequent care were designed to have simple numerical or yes/no answers. The number of families completing these questions as a percentage of the number of children for whom the questions applied could thus easily be calculated. For the more open-ended, qualitative questions it was not possible to identify the proportion of eligible families who had completed the question.

For the numerical / yes-no questions the proportion of families answering each question ranged between 86% (“How long was it from commencing LTV until discharge home”), and 100% (e.g. “Has he/she been discharged from hospital?”, and “did you feel adequately prepared for discharge?”).

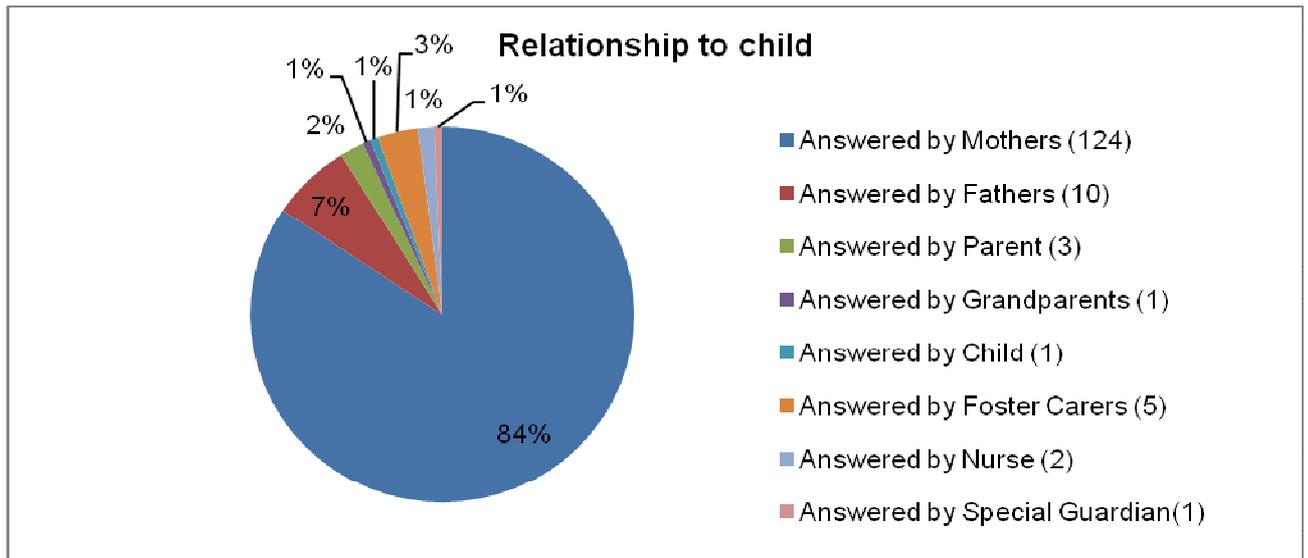
All other questions in this category were answered by between 88% and 96% of families.

Person completing the questionnaire.

The relationship between the person completing the questionnaire and the child on LTV is shown in Figure 1 below. In general the quality and completeness of questionnaire completion was highest for

mothers, slightly lower for fathers, and the one child who completed the questionnaire unaided had the lowest number of completed questions. In general both mothers and fathers tended to miss out the same questions.

Figure 1: the person completing the questionnaire.



2. Demographics

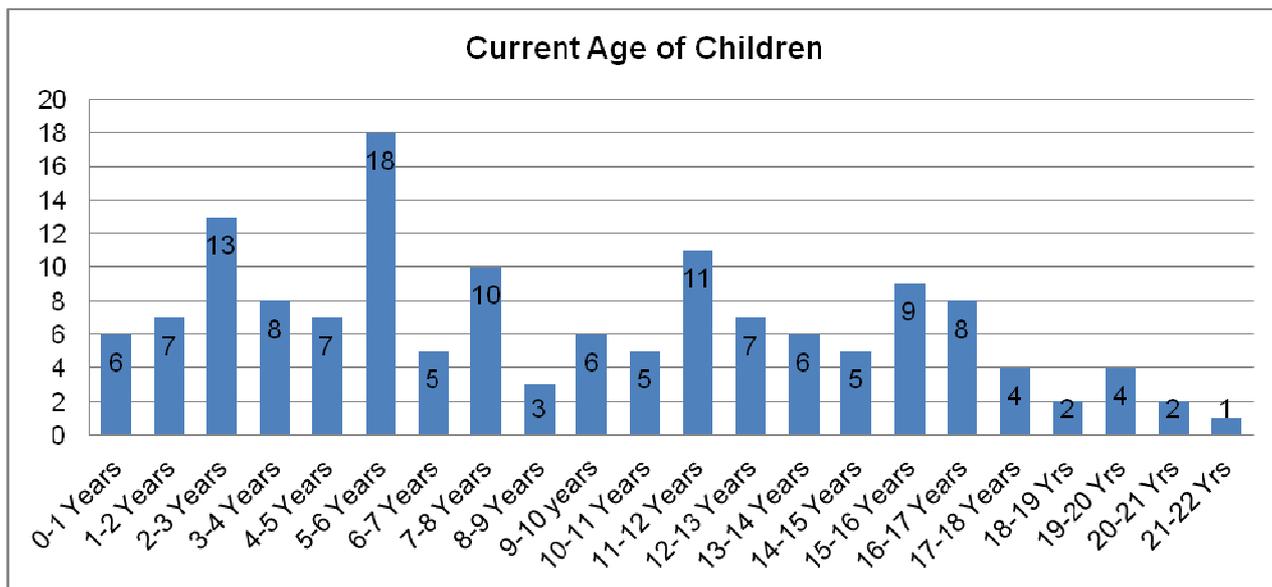
Sex of child on LTV

Of the children on LTV included in the study 43% were girls and 57% were boys.

Current ages of children

Figure 2 shows the ages of the children at the time the questionnaires were completed.

Figure 2. Ages of children on LTV

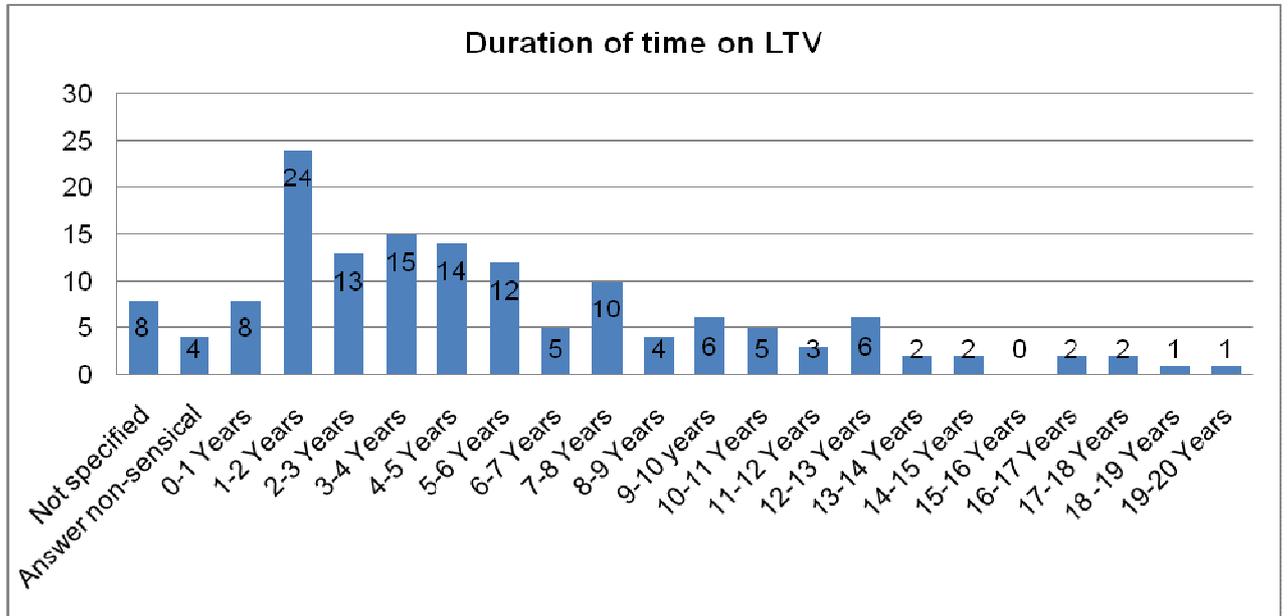


From these data it can be seen that although the questionnaire requested information only from families of children who had commenced LTV before the age of 18, some families whose children on LTV had passed this age also completed the questionnaire. As all of these children/young people had commenced LTV before the age of 18 the data from these families has been retained in this report. The median age was 7 years [iqr:4-13 years]. Overall the sample includes children at all ages in childhood, though a smaller proportion in the older childhood/adolescence age group than would be anticipated from the recent national study by Wallis et al²

Length of time on LTV

The length of time the children have been receiving LTV is shown in Figure 3. The time ranged from a few months to 20 years with a median of 4 years [iqr:2-7 years].

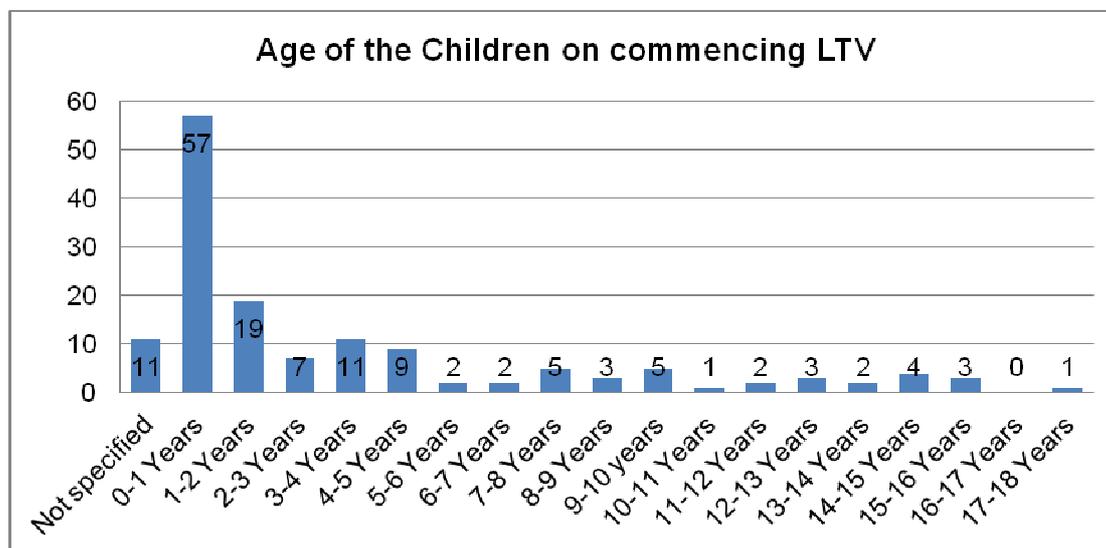
Figure 3: Length of time on LTV.



Age when LTV commenced

The ages of the children at the time they commenced LTV is shown in Figure 4. The ages ranged from a few months to 17 years; the median age was 1 year [iqr:0-4 years].

Figure 4: Ages of children when they commenced LTV.



The families who completed the questionnaire included a higher than anticipated number of children who commenced LTV in infancy, and relatively few who commenced in adolescence (e.g. those with Duchene dystrophy or other progressive neuromuscular conditions).

Current Location of child

29/ 147 families did not answer this question. Of those that did, 105 (89%) were currently at home at the time of the survey and 13 (11%) were still in hospital.

Geographical distribution of families completing the questionnaire.

The geographical distribution by Strategic health Authority area of the 143 families who gave this information is shown below.

Although the study was intended to include only England, 2 families from Scotland completed the questionnaire, and their data has been included in the totals for all sections that they completed.

Strategic Health Authority	Number of families with Children on LTV who completed the questionnaire
CHANNEL ISLANDS	2
EAST MIDLANDS	21
EAST OF ENGLAND	9
LONDON	13
NORTH EAST	9
NORTH WEST	15
NORTHERN IRELAND	1
(SCOTLAND	2)
SOUTH CENTRAL	18
SOUTH EAST COAST	5
SOUTH WEST	25
WEST MIDLANDS	11
YORKSHIRE & HUMBER	12
	<hr/>
TOTAL	143

Reason for LTV

The questionnaire initially used the same classification system as that used by Wallis et al² for defining the underlying reason for LTV - i.e.: Central Nervous System, Respiratory, Neuromuscular, and 'other'. If parents were not sure which category applied to their child they were asked to give as much clinical information as they could to allow us to categorise the condition. The replies we received did not easily fit into the Wallis classification, as several families noted a primarily cardiac underlying cause, and many families gave more than one underlying condition, so that for the 147 children we had 232 answers. On the basis that most children needing LTV for an underlying cardiac condition were likely to have a secondary

respiratory problem we changed the “respiratory” category to “cardiorespiratory”. Using this slightly modified classification the percentage of entries in each category is given below. For comparison, the figures given in the Wallis study² are given in brackets:

Central Nervous System:	34%	(18%)
Musculoskeletal	21%	(43%)
Cardiorespiratory	38%	(37%)
Other	7%	(2%)

Although the distribution of the major underlying conditions differs from that in the much larger study by Wallis, the sample does include a reasonable sample from each of the major categories of underlying conditions.

LTV interface

The numbers of children receiving LTV via the various routes (Tracheostomy, Mask, nasal prongs or pillows) are given below. The comparable figures from the Wallis study² are also given for comparison:

	This study:		Wallis et al ²
Tracheostomy	67	(46%)	212 (22%)
Facemask	66	(45%)	696 (75%)
Nasal prongs	6	(4%)	
Not specified	8	(5%)	25 (2.7%)

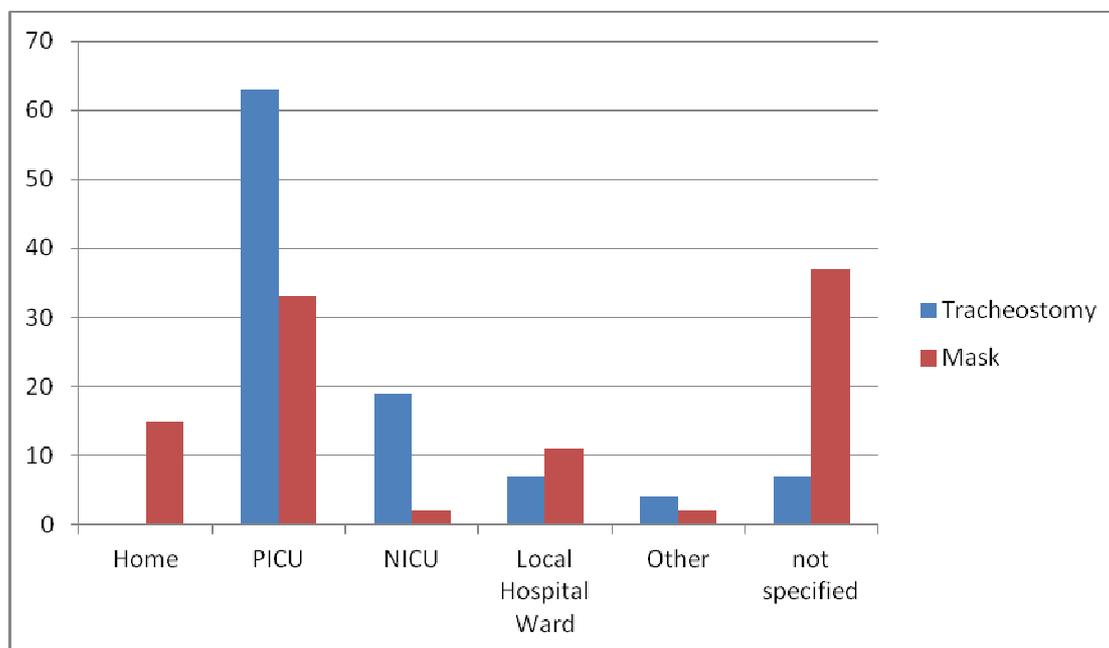
Of the children with tracheostomies, 3 also had phrenic nerve pacemakers, and 1 was receiving negative pressure ventilation.

The relative over-representation of children receiving support via a tracheostomy in this study compared with the Wallis study may be a consequence of the higher dependency levels of such children. These families might be under greater pressure and perhaps for this reason be more willing to contribute to this study.

Where was LTV instituted?

Families were asked about the setting in which LTV was instituted. For most children receiving LTV via a tracheostomy this was in either a paediatric intensive care unit (PICU) or a neonatal intensive care unit (NICU). Some children receiving non-invasive ventilatory support via a facemask commenced LTV at home, and very few did so in a NICU. The percentage of children in each group who commenced LTV in the various settings is shown in figure 5.

Figure 5: Percentage of children in whom LTV was instituted in different settings

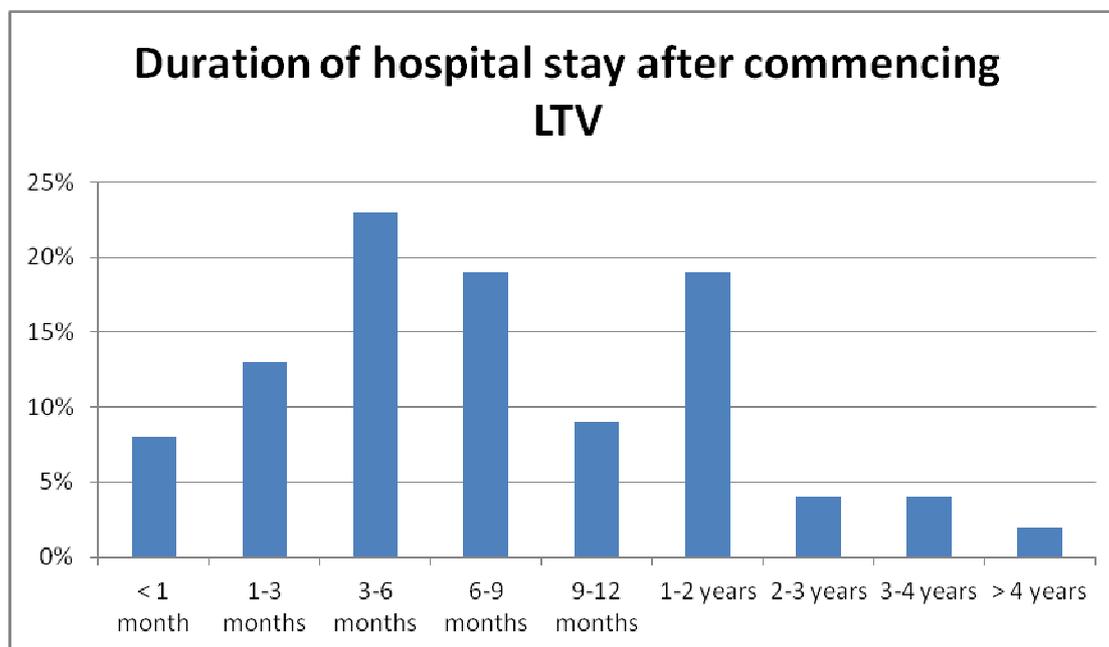


For the majority of children receiving LTV via a tracheostomy (82%) it was instituted during a hospital admission to NICU or PICU in which the child could not be weaned from ventilation, whilst for those receiving non-invasive ventilation via a mask LTV was most commonly (70%) commenced after a clinic visit or investigation such as a sleep study, though the process of institution of LTV was commonly conducted on a PICU. Amongst the children on non-invasive LTV, 19% were in an intensive care unit and unable to be weaned from a ventilator.

3. Children receiving LTV via a tracheostomy.

For those children in whom invasive LTV via a tracheostomy was initiated during the course of a hospital admission, the length of hospital stay after the decision to institute LTV had been taken varied widely, as shown in figure 6. The median length of hospital stay was between 6 and 9 months, but for some children it was much longer.

Figure 6. Duration of hospital stay after commencing LTV via a tracheostomy



For children receiving LTV via a tracheostomy the most important factor (identified by 40% of the parents) causing or contributing to delays in discharge was recruitment and training of carers, whilst 31% of parents identified training for family members as contributing to such delays.

Of the 51 families with a child receiving LTV via a tracheostomy who had been discharged from hospital, the great majority reported having felt emotionally (78%), physically (89%), psychologically (72%), and educationally (85%) ready for the discharge by the time it occurred.

Whilst 88% of families with children receiving LTV via a tracheostomy reported having received resuscitation training prior to discharge, only 2% reported having been given an instruction manual for the ventilator.

In the process of planning for discharge from hospital, 8 (17%) of these families reported that regular meetings were held to ensure progress was maintained, 9 (20%) reported having a discharge coordinator, but only 5 (11%) reported having an agreed follow-up plan at the time of discharge. Staged discharge (i.e. going home initially for a short time followed by planned readmission before final discharge) was reported by 8 (17%) of these families. 22 (52%) families reported that they felt their child was directly involved in an age-appropriate way in the preparations for discharge.

Families described a number of particular concerns surrounding the process of discharge from hospital. Many reported difficulties arising because of a lack of communication between the hospital and community care teams, others reported feeling ill-informed about what would be required of them after discharge, and several reported feeling that they had insufficient information about how the heart and lungs worked, and the role of the ventilator.

Several families reported having to push very hard to persuade the hospital team that it would be possible to care for their child at home, whilst most were very positive about their relationship with the medical and nursing teams providing care in hospital and the efforts made to prepare them for discharge.

Those families who had a discharge coordinator were almost universally enthusiastic about the role this person had, and the way it helped ensure a smooth transition from hospital to home – particularly the liaison role in ensuring the community care team was fully prepared and informed.

Several families commented on how helpful it had been to have contact with another family with a child on LTV before discharge, to gain some direct information about what would be involved, and how it might affect their lives. Several also commented on the importance of looking after themselves in the period before discharge, to ensure they were emotionally and physically able to cope with the demands of having a child at home on LTV. Several families commented on the importance of having an adequate care package in place before discharge, and the extreme difficulties they experienced in trying to increase the level of funded care if the initial plan was not adequately resourced.

After discharge from hospital the outpatient follow-up arrangements varied widely. The great majority of these families reported being seen on a regular basis in outpatients after discharge from hospital – most commonly (86%) by a respiratory paediatrician or paediatric intensivist, usually at 3-6 month intervals, but only 39% reported regular contact with a children's nurse specialist in LTV. Those families who had contact with a specialist nurse in LTV were very positive about the benefits of such contact both in terms of improved communication between the families and hospital based specialist paediatric services and in terms of ensuring the appropriate provision and maintenance of equipment and services at home. In this context several families commented on the helpful role of the nurse specialist in ensuring their care package was not arbitrarily reduced or withdrawn, and several also commented on the value of this expert support in helping them to care for their child with limited additional care or resources.

Of the 67 children receiving LTV via a tracheostomy 36 (54%) had been readmitted to hospital during the past year (or since discharge if less than a year). Of these readmissions, 26 (72%) were primarily because of a respiratory infection, including 10 (28%) who were admitted more than once; 2 (6%) were solely because of problems with the ventilator or other equipment, and 8 (22%) were planned

readmissions for further investigations. Parents commented that for 3 of the readmissions for respiratory infections the problem was compounded by a lack of appropriate staff to provide care at home, leading to an admission that might otherwise have been avoided.

4. Children receiving LTV via a face mask or nasal prongs.

As noted above, 70% of these children had commenced LTV as a result of investigation or observations at a clinic visit or as a result of a sleep study. The process of commencing LTV was thus commonly more planned, and prolonged hospital stays after commencing LTV were uncommon. A total of 54 families gave detailed information about the discharge planning and post-discharge care arrangements for children receiving LTV via a face mask or nasal prongs. In the process of planning and organising discharge from hospital, more families in this group (57%) than in the tracheostomy ventilated group (17%) reported that regular planning meetings were held to ensure progress was maintained. 43% reported having a discharge coordinator (versus 20% in the tracheostomy ventilated group) and 84% (versus 11% in the tracheostomy ventilated group) reported having an agreed follow-up plan.

Although a higher proportion of these families (26%) than families of tracheostomy ventilated children (2%) reported having been given a copy of the ventilator instruction manual, only 46% reported having been given training in resuscitation. A significant factor identified by families as causing or contributing to delayed discharge (in 22%) was training for parents or other family members. Only 15% cited recruitment or training of carers as contributing to delayed discharge.

Parents' comments on difficulties and problems that arose during the discharge planning process focussed on the difficulties in ensuring good communication between the community and hospital teams, ensuring that community-based professionals and carers were adequately educated and informed about the technical and practical aspects of LTV, and ensuring that community based professionals had a good understanding of the nature and prognosis for the condition from which the child on LTV was suffering. Families with a discharge coordinator commented that one very important part of the role of this individual was to prevent such difficulties arising.

The families of children receiving non-invasive LTV via a facemask were also very clear in their view of the value and potential benefits arising from families being able to meet and talk to other families with children on LTV, if possible before commencing LTV for their child, but certainly before discharge from hospital.

Most children in this group were regularly seen in outpatients for follow-up by a respiratory paediatrician or intensivist (67% vs 86% of those ventilated via a tracheostomy), and the frequency of such visits was, as for the tracheostomy

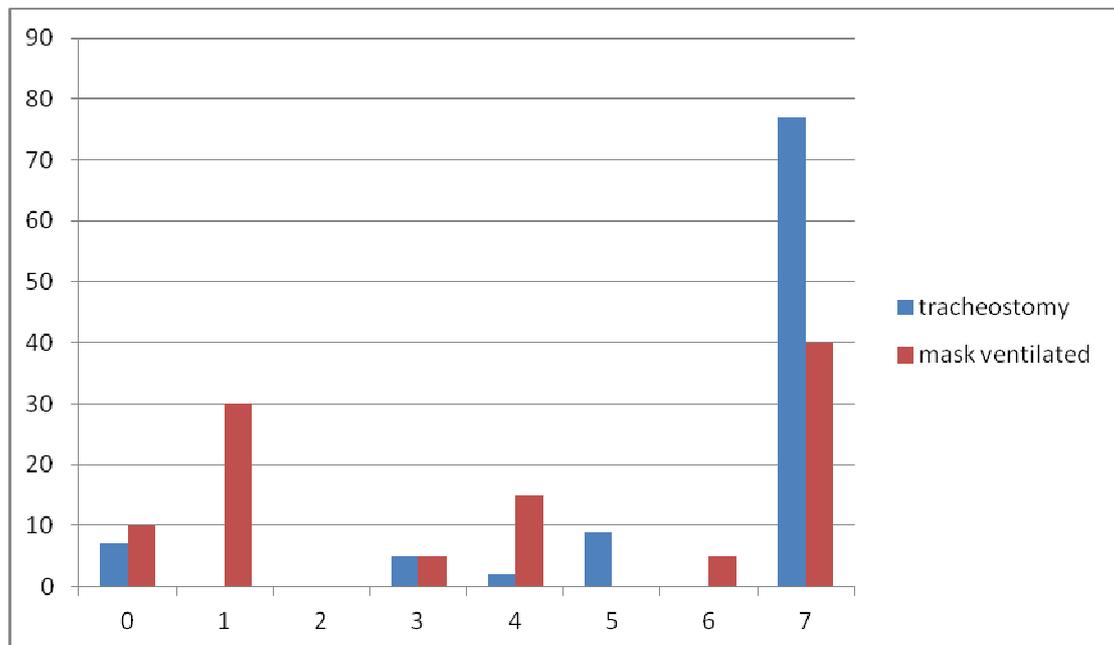
ventilated children mostly 3-6 monthly. A similar proportion of families in this group as in the tracheostomy ventilated group (35% vs 39% respectively) had regular contact with a children's nurse specialist in LTV after discharge, and as for the tracheostomy ventilated group, these families were universally positive about the benefits of such contact.

Several families were concerned about the difficulties they experienced getting adequate support from independent care companies and home oxygen supply companies, and noted the adverse effects on quality of service that arose from frequent changes of contract to supply oxygen or other community services between companies.

5. The care of children at home on LTV.

A total of 80 families reported that they had an agreed care package, with support provided on a variable number of nights per week as shown in figure 7.

Figure 7: The percentage of children receiving care packages at home for 0 to 7 nights per week



The care packages were provided by a wide range of NHS and independent agencies, and 26% of families reported that they had experienced at least one change of care provider during the period of LTV.

Only 10% of families reported that they organised their own care package using the direct payment scheme, but 30% of families expressed an interest in doing so.

Of the 64 families who answered the question "What provision if any is there in the care package for you to have time out with your partner", 35 answered "none" and others gave answers ranging from one hour per week to 4 hours per week. A few families had care packages that allowed parents an evening or night off together ranging from once a fortnight to once a month. Most care packages gave no specific allowance for parents to spend with other siblings. For families designated respite time could be used for parents to spend time together or with other children.

When asked about what training they had received after discharge from hospital, 110 families responded, but only 3 families described receiving a regular annual update on resuscitation and other aspects of the care of their child. The great majority of families described having been shown how to use the ventilator and other relevant equipment before discharge, but many expressed concern at the complete lack of any such further or refresher training after discharge. Many families had only received training on how to use the ventilator from the company sales representative when delivering the ventilator. One family described how they ensure they are up to date by joining part of the resuscitation and care training given to new carers, whilst other families describe having to teach some aspects of care to new carers themselves. Another parent stated that:

"I put myself forward to regular BLS training but I have never been offered it since I left hospital. My skills are never checked".

When asked about training offered or given to other family members who are or may be involved in the care of the child on LTV 85 families responded, of which only one family described an annual refresher course on resuscitation training. Several families noted that they had trained their relatives themselves, whilst others described training of a similar standard to that given to the parents, before discharge, but no subsequent refreshers or assessment of competence.

In response to the question "were you given easy-to-understand written instructions about various items of equipment such as the ventilator, and about how to look after the face mask or tracheostomy?" 93 families responded, of whom 36 (39%) said they had not been given such instructions.

Whilst most families (80%) said they were not involved in the selection or recruitment of their carers, over half (52%) of the families who responded said they were involved in the training or teaching of the carers, and 64% said they always met new carers before they arrived for their first shift. For 66% of families the role and responsibilities of carers were said to be well defined and clear, but 68% of families

said they had experienced some problems with unreliability, language difficulties, alcohol use or inappropriate behaviour of carers on at least one occasion. Many families (63%) said they were able to contact or leave messages for carers when they were not on duty, and 62% said they were sometimes able to leave their child in the unsupervised care of a carer (i.e. they could sometimes go out for a while when the carer was present in the home).

Families were almost universally positive about the relationship they and their child had with the regular carers, many describing how important these relationships were for the child and the family. Several families noted that unfamiliar carers, too many changes in the team in a short time, or repeated use of agency staff was very stressful and disruptive for the child and the family, with parents sometimes unable to go to bed because of the concerns of the child in such settings.

Whilst two thirds of the families reported some difficulties in transporting their child plus equipment, most could fit all of the necessary equipment plus children in their car, and most said they had enough storage space at home, and knew who to contact if repair or servicing was required unexpectedly.

Of the 94 families who answered the question, 87 (93%) reported that they received Disability Living Allowance, Carers Allowance or other relevant benefits.

Many families (68%) reported having to take extra time off work on a recurring basis, and of the 93 families who answered this question, 68 (73%) reported one or both parents having to give up a career or job to look after their child.

Overall, 64 (70%) of the 91 families who answered the question about the quality of their support at home felt that their support was generally good.

In extensive 'free text' commentaries, families described the complex, demanding and difficult adaptations they had to make on a daily basis in order to ensure their child received good care. The financial hardship experienced by many families because of the extra cost involved in caring for their child and, for very many families the necessity of one parent being at home most of the time made many normal family activities almost impossible. Some families reported that, although offers of help and support were sometimes forthcoming from professionals or agencies, the reality was often that such offers invariably did not come to fruition. Such repeated disappointments were described in very moving terms by several families. 22% of the families were single parent households, and for them the problems with support and respite were particularly severe.

School

A total of 76 families had children on LTV who attended school, and the great majority (68/76 - 92%) reported receiving good support from the school. Parents reported that for 70 (92%) of the children the school encouraged interaction with

other pupils, and 44 (58%) explained to other pupils about the special needs of children on LTV - e.g. the tracheostomy. The great majority of children received some additional classroom help in the form of a teaching assistant or carer for part or all of the time.

Siblings

108 families reported that there was one or more other siblings in the household, and for 19 families one or more of the siblings also had special needs.

Parents' needs

Parents were asked if they each had any time for activities specifically for themselves, and most parents (both fathers and mothers) reported very little such time, though many made complex arrangements to allow themselves some time off. For many families the two parents had to "cover" for each other so time off together was uncommon.

Respite care

Few families (30%) reported that their child had been away for respite care to a children's hospice or similar, though most of those reporting such breaks were very positive about the benefits. Some families reported only being able to use Hospice facilities as a family whilst others reported being able to choose whether they accompanied their child. For families with other children the lack of support for the care of the other children - or of allowing parents to spend dedicated time with other siblings - was a recurring theme. Several families commented on the difficulties in maintaining standards of care whilst in the hospice because of the complexity of their child's condition, though none reported that this was a reason not to take up stays in the Hospice. Many families reported that they were unable to take up the full number of potentially allocated nights' stay because of very heavy demand on Hospice resources.

Family holidays were also commonly reported to be a major difficulty, with only 39% families reporting that they had ever been away on a family holiday since their child commenced LTV.

Aspirations of Families

Families were asked to give a free text answer to the question ***“is there any additional help or support that you think would improve the quality of your life or that of your child?”***

A total of 75 families responded, and their answers identified a number of recurring themes which are summarised below, in approximate descending order of frequency though there was considerable overlap:

1. Many families expressed a wish for an additional carer at times, to allow the parents some time – either to be with other children, to be alone together, or just to have some occasions when one or both of the parents did not always have to be with the child on LTV.
2. Many families also expressed a wish for more respite care or time – either access to care in a hospice or equivalent, or additional support so that the family could have time together away from their normal day to day responsibilities for a few days, or for regular shorter periods.
3. A similar proportion of families expressed the wish to have someone who was well-informed about what grants, support, allowances they may be entitled to. They emphasised the complexity of the rules governing such financial support, and for many the lack of help in identifying their needs and how best to support these was a major problem. Many families noted the relative lack of help, support or advice from Children’s Social Care.
4. For many families merely being able to pay their regular utility bills was a major problem. Many noted how high their electricity bills were, partly as a result of the continuous running of equipment and the need to always have lights on, and also their child’s perceived vulnerability to cold and the consequent need to keep the home warmer than would otherwise be the case.
5. Related to the cost of running equipment at home was the space necessary to store, run and maintain their equipment, together with the extra space need to care for a child with a disability. Difficulty or inability of families to obtain support to move house or to expand their accommodation to meet these needs was a common theme.
6. Other families noted that the difficulties they experienced in getting community based nursing, physiotherapy or equipment technical support made their lives more difficult, and sometimes led to potentially avoidable hospital admissions.
7. The practical difficulties in getting around with a child in a wheelchair – particularly the near impossibility of using public transport in many areas, the lack of appropriate access to public buildings, and the difficulties posed by trying to go outside with a child on a ventilator when it was raining
8. A further theme running through many families’ responses was a wish for professionals and the general public to be better informed about the needs of children on LTV to ensure the children and their families were treated with appropriate consideration and forethought.
9. Some families who had control of their care budget through the direct payment scheme commented that this gave them greater freedom to adjust their care package as required, though inadequacy of overall funding was still sometimes an issue

Finally, families were asked to give a “wish list” or things they would really appreciate, from the small to the huge. The responses from the 95 families who completed this question are reproduced as appendix I. Most families wanted small things to allow them to lead a slightly more normal and less demanding life for at least a small part of the time.

Discussion.

The increasing numbers of children receiving long term ventilator care at home and the particular needs of these children and their families at a time of decreasing public expenditure means that it is of the greatest importance to identify current patterns and standards of such care and the ways in which this is or is not meeting the needs of the children and their families.

This is the first national study to obtain information on the views and needs of families in England with children receiving LTV, and the families who responded were widely distributed geographically.

In the present study, only one third of the families invited to participate completed the on-line or paper questionnaire. It is therefore not possible to say how representative their opinions are of those of the population of families of children on LTV as a whole. However a one third completion rate for such a complex questionnaire (which took at least 30 minutes to complete) is a good response rate for such a study.

This study clearly shows the high level of commitment that the families of children on long term ventilation have to sustain over very prolonged periods of time. Despite the strains that such demands make on personal and family life however most families remain very positive and constructive in their suggestions as to how the services could be improved.

Parents were generally very positive in their assessment of the quality of care given to them by hospital and community based NHS services, but many expressed frustration and irritation at the lack of any consistent nationally available guidance on how to achieve rapid and effective transition from hospital to home. The processes of discharge planning and organisation were commonly hampered by a lack of experience in the Health care staff. Many families noted the apparent need to “reinvent the wheel” for each child.

This survey identifies a number of ways in which the care given to children on long term ventilatory support and their families can be improved, most of which do not have significant cost implications, and some may allow more effective use of limited resources without increased cost.

These are summarised below.

Suggestions on ways to improve the care of children on LTV and their families, arising from the families' answers to the questionnaire:

1. Discharge planning co-ordinator

In line with current approaches to planned discharge from both neonatal and paediatric Intensive Care, it is clear that the process of planned discharge for children in hospital receiving LTV should start immediately it is clear (or a reasonable possibility) that LTV at home will be required.

The appointment of a coordinator with the specific role of facilitating and organising the process of discharge was universally praised by families for whom such a role had been created, and others commented on the adverse effects that became apparent to them because no professional had explicitly taken this role.

2. Adequately funded care package

The importance of agreeing an adequate (and adequately funded) package of care as soon as possible, with regular review after discharge when it may be possible to reduce parts of the package was suggested by several families. The cost differential between hospital and home care – even with a relatively extensive package of home care – is considerable, and families noted that trying to achieve discharge with an inadequate package commonly led to prolonged delays and thus potentially greater expenditure on hospital care (or opportunity costs to other families because of “bed-blocking” by the child on LTV).

3. Closer engagement with Social Care

In the process of organising packages for care at home, and in supporting families once discharge has taken place, many families noted the relatively small involvement of Children's Social Care. The overwhelming and complex medical needs of some children on LTV seems to lead to a failure of multiagency working, with NHS staff not able to provide some of the additional social care family support that may make the difference between a sustainable arrangement and one that repeatedly breaks down leading to readmission to hospital. Continued involvement of knowledgeable professionals from Children's Social Care to ensure families receive all appropriate financial support as well as organised social support and care was noted by the small number of families who had received such support as being of very great value.

4. Improved provision of respite care

The lack of support or consideration of needs of the parents and of other siblings was noted by many families as being a major stressor. The effects of such stress within the family were noted by many families to be one of their greatest difficulties.

Regular respite care either to allow the family to spend time together in a supported place away from home (e.g. a hospice) or to allow parents and other siblings the chance to enjoy some family time was a recurring theme in the parents' responses. The pressure on places in children's hospices, and the policy of not allowing families to use such facilities if it was perceived that the affected child's prognosis had improved commonly made it almost impossible for families to achieve respite away from home, and the only option available to some such families was planned, semi-elective readmission to hospital of the child on LTV.

5. Improved communication between professionals

The lack of good communication between hospital and community-based professionals, and the lack of understanding by hospital professionals of how community-based care is organised and provided sometimes led to difficulties for families who felt they were stuck in the middle and having to "translate" between the two groups of professionals.

Such communication difficulties and the lack of any identified community based contingency resources led to major difficulty in obtaining temporary increases in community based care packages to cover illness or other family crises, resulting commonly in children having to be readmitted to hospital in order to receive additional care such as physiotherapy.

6. Continued training

Many parents expressed concern at the lack of any apparent programme of continued training for parents and other lay carers, who recognised that, even if they had been given some training when their child first went home from hospital this should be regularly up dated and reinforced.

Appendix I Parents' wish lists.

	Q 294: Make a "wish list" of things you would really appreciate from the small to the huge! (e.g. a chance to have a coffee out with a friend, a countryside walk, a massage, time to sit alone and read a book, dinner out for a whole evening, w/e away, holiday with/without ventilated child and with/without other siblings)
1.	more space for my children massage holiday with the family with support
2.	I don't like being away from my children, a family holiday would be nice but we can no longer afford one, I feel we need some bonding time.
3.	coffee out with friends, time to sit alone,
4.	Yes all of the above. And perhaps not having to beg for help from the pct or social services, that would be good.
5.	massage, dinner out family holiday would be fantastic
6.	A HOLIDAY WITH ELDEST SIBLING, DE STRESS, DETOX, A REALLY GOOD FRIEND TO SHARE THE HIGHS AND LOW. LASTLY A PARTNER.
7.	join a gym, a bath and i would love a lie in past 7.30am as this never happens.
8.	A half day a week to go out on my own. More trained staff to enable me to take my daughter out to different activities, whilst Oliver is being cared for by others.
9.	to be honest to stop feeling so alone. for Mxxx to experience special things. have my hair done without feeling guilty about leaving hubby alone with Mxxx who really needs 2 people with him at all times
10.	A family holiday
11.	a family holiday
12.	More couple time. It would be lovely to go out for a meal in the evening with my husband and not have to worry about our Son being looked after properly. Relaxation time is also in high demand but rarely obtainable. Holidays are few and far between and we always have to go with our parents as they pay for most things and also help with our Sons care. It would be nice to be granted a carer for our holidays instead of having to do 24/7 the whole time we are away. You feel like you need another holiday to recover afterwards due to the lack of sleep.
13.	Go on holiday with my kids Go to college
14.	A PROPER HOLIDAY FOR JUST MUM AND DAD, VISITNG AREAS OF INTEREST FOR BOTH OF US MUM GARDENS AND MYSELF HISTORICAL BLDGS/ENGINEERING MUSEUMS.
15.	a holiday away/evening out would be nice or a pamper day.
16.	would like to take all boys to Spain, time out with husband, better weather in England (so Cxxx can go out for more than an hour !)
17.	Weekend away as a couple. Chance to visit grandparents with night care provided.
18.	Time to just sit for a couple of hours, time to catch up on sleep if had no care/ been up with a poorly child, to be able to have a lie in in a morning past 7.15am, to have my own house to myself occasionally on an evening, without carers being sat there, to have a couple of days total break every now and again, just a complete rest!
19.	holiday abroad with child so he could go on an aeroplane
20.	holiday together, family holiday, time alone, coffee with friends, dinner together, time to sit on beach, time to surf, swimming

21.	We are going on holiday to Italy in May - I wish we didn't have to take the machine - I would love to not have to put it on and hear it beep during the night!
22.	a family holiday with Sxxx but with support i.e staff
23.	w/e away ,with ventilated child and other siblings and a massage
24.	A meal out with Hubby in the evening. A family holiday with enough care for us to really enjoy things. A cleaner regularly enough to keep the house clean and tidy.
25.	We would not like to do anything without our child and we are keen to involve him in any part of our lives. We have taken him on short breaks to visit family etc and this is very important to us (we take full responsibility for his care at these times, and although it is tiring it is worth it). If we had a wish it would be that I could return to work (at least part time) at some stage in the future but that looks impossible at the moment.
26.	any of the above would be nice
27.	yes a massage, holiday, my ironing done upstairs toilet and downstairs extended to get the wheelchair in when needed, not to have to beg for the deposit for the motability car
28.	holiday
29.	A longer time away on holiday than a long weekend. At present we get away individually but never manage to get more than 3 or 4 nights away together for fear of carer illness, etc
30.	holiday with all children with care support, chance to walk the dog without carrying/pushing half a hospital, chance to decorate and sort out my house
31.	holiday without any children just pure respite!!
32.	A cure
33.	a day or weekend away with just friends.
34.	a holiday with our son as i am finding it difficult to find a place to stay this year as we need hoisting and a special bed and the place i have looked are so expensive. a chance to have time to myself without the constant worry of the phone ringing regarding our son.
35.	Evenings out would be nice
36.	go for a walk, shopping, take other children on outings a family holiday
37.	a family holiday
38.	dinner out, just to be able to up and go away for the weekend at short notice, to be able to have a night out as a family without having to clock watch as care team arriving
39.	Being able to get away as a family.
40.	Not having to get up in the night to turn Pxxx!
41.	A family holiday
42.	time with husband, more time to help other children
43.	a soak in the bath
44.	my daughter is paralysed from the neck down. time to myself would be good I have to do everything for her
45.	Time to go on a holiday without children time to go out for a meal Visit family in India

46.	to go on holiday (without having to pay for the carer to come as well) to find a job that I can to within school hours and term time only to make some friends a night away with my partner as we have never had a night alone
47.	would love to manage a holiday with the children. Also would like to go on holiday with friends
48.	holidays with ventilated child
49.	chance to attend a hobby like photography course. a good nights sleep.
50.	Be able to go on holiday but with child and some play area for the child at home (special swing and soft play area.
51.	A tarmac drive - no gravel.
52.	firstly to go swimming ,have a massage and just relax on my own, away on holiday without ventilated child though it's a hard decision and lastly can have the dinner out.
53.	holiday with ventilated child and the whole family, dinner out for the whole evening. More trained support with child during school holidays
54.	Help with the house, time on my own - fulfilling some lifelong ambition, time with each of my children on their own, time with my husband but knowing the children were fine. Someone to shoulder more of the practical things and decisions - an au pair would always have been nice!
55.	Going out as a couple, Going out as a family, being able to get Jxxx in to family and friends houses, being able to just nip out quickly without having to load the van up first, not having to deal with PCT or other health professionals, not having to go to outpatient appointments, not to have two disabled children, not to have a terminally ill child, I would love for Jxxx to be able to walk. I would like to take Jxxx travelling around the world. I wish Jxxx was healthy. The list could be endless.
56.	any thing really just glad to have some kind of break from all the anxieties
57.	All of the above sounds lovely!
58.	Dinner out with my husband on our own with out having to worry about home. Holiday abroad with all off us.
59.	Holiday with children Go to cinema with husband
60.	RESPIRE, RESPIRE, RESPIRE! For my son to go away for more overnights and let me have SLEEP/PEACE/CHOICE TO GO OUT WHERE I WANT & WHEN I WANT. TO BE ABLE TO WORKAND NOT HAVE TO ASK SOMEONE ELSE FOR HELP WITH MY SON JUST TO BE ABLE TO LEAVE THE HOUSE.
61.	A night off!!!!!! Time to read a book
62.	my life is great
63.	Pampering session. Hair Done. Full nights sleep. Dinner out and a grown up evening.
64.	a holiday with my ventilated child!
65.	A weeks holiday away without any children, whilst someone took full time care of my son, whom I trust implicitly, so I would not be worried. When he is off sick from school, someone to come and take over for a few hours, so I can do my cleaning or just have 5 mins peace. A weekend away with my 17 yr old daughter.
66.	Time alone in my own home, without there being other people there a lot of the time, especially evenings.
67.	more hours in the day

68.	holiday massage reading
69.	Horse riding. Meeting up with friends. Weekend away with husband.
70.	a car, some respite, counselling for the whole family, someone to talk to who knows what we are going through, a bath in peace, cross stitch, spend time alone with husband, a good night's sleep, Bxxx not to be ill,
71.	If i was to have a wish list, it was that my child had a clean bill of health to be honest, however I would like family quality time altogether away from the home to give us all time to spend together and have a bit of fun
72.	I would really love for us as a family to go to Disney land Paris as a special treat for my children. My older daughter worries a lot for lxxx and has seen what she has been through and loves her more than ever. Time to sit alone and read a magazine, paint my nails in peace, go out as a couple for meal etc etc
73.	A holiday with my husband and both children would be nice
74.	going on holiday with daughters going out for dinner long walks seeing friends and family
75.	You can only have very short breaks. Sometimes taking a break makes it more difficult to get back into the swing of things.....on your return. Its a frustrating situation and I find the lack of spontaneity adds to this. This is 12 years on caring for my child.
76.	We would love to have a double BUPA shift every now and again so that we can go out with our extended family all together instead of one of them having to babysit with the BUPA carer - e.g. weddings, special birthdays.
77.	This is the thing really I genuinely don't want to be without my daughter, but would love to, say, go on a bike with my son whilst someone else pushes the wheelchair alongside. I would feel guilty and would not enjoy all the above as I would constantly worry about my daughter. It is a bit obsessive but it comes with the flashbacks of almost losing her quite a few times. I am not only the best one to care for her because I am her Mummy, and understand her unique methods of communication but I have 20 years experience in nursing critically ill children, especially respiratory illnesses. And she deserves the best!
78.	weekend or holiday away for all the family and for just myself and husband
79.	Jxxx has been trachy free now for four and a half years now but thinking back i would of loved to have had time to just read a book or go out for dinner with my husband and not had to worry about Jxxx.
80.	My wish would be to have a normal life whatever normal is. That's not possible I know I would like my life not to revolve around the staff rota that drops through my door each week.
81.	Evening out as a couple (at cinema, playhouse and restaurant).Holiday away as couple and time to read and do own hobbies.
82.	Unbroken sleep!
83.	Unbroken sleep
84.	time on our own, having all the family sleep upstairs and go on holiday
85.	A massage, dinner out in the evening, holiday with child
86.	time with self/partner/siblings. holiday altogether
87.	we would love a holiday. I would just love to do what other parents are able to do
88.	Someone to do more training with the carers. Ensure they know what they are doing and they haven't forgotten to do things.

89.	don't really like to make these kind of lists!! feels like I'm wishing for the impossible sometimes!
90.	would like to give surprise party for 21st birthday
91.	* A mobility car so we could do more things with Bxxx (not entitled to one until he is 5). * A bigger house to fit all the extra equipment in. * Bxxx to go to mainstream school when he is old enough
92.	it would help if we got mobility to help with the running of our car
93.	more space at home re decorate and new furniture holiday
94.	Respite for teenagers with complex medical needs only.
95.	an evening out with my husband

References

1. Jardine E, O'Toole M Paton J, et al Current status of long term ventilation of children in the United kingdom: Questionnaire survey. *BMJ* 1999;318:295-9
2. Wallis C, Paton JY, Beaton S Jardine E . Children on long-term ventilator support: 10 years of progress. *Arch Dis. Childhood*. DOI 10.1136/adc.2010.192864
3. Goodwin S, Smith H, Langton Hewer S, Fleming PJ, Henderson AJ, Hilliard T, Fraser J Increasing prevalence of domiciliary ventilation: changes in service demand and provision in the South west of the UK. *Eur J. Pediatr*. 2011; 170: 1187-1192