



# LRI Children's Hospital

## Initiation of Long Term Non-invasive Ventilation UHL **Children's Medical Guideline**

Staff relevant to:	Pediatric Respiratory and long term ventilation team
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## **Contents**

1. Introduction and Who Guideline applies to2
2. Definition and circumstances
Table 1: Levels of need of children initiated on LTV
3. Suitability:
4. Preparation of the family and Child:4
5. Initiation:4
6. Equipment5
7. Progress and monitoring:7
8. Discharge Planning7
9. Follow up:
Education and Training9
Monitoring Compliance9
Supporting References10
Key Words10
Pathway for discharge of long-term non-invasive ventilation in children
SLEEP STUDY (POLYGRAPHY) REFERRALs 11
Ventilation Prescription11
Ventilator Training Checklist 11

## 1. Introduction and Who Guideline applies to

The number of children requiring long term ventilation to maintain respiratory health has increased exponentially in the past 20 years <sup>(1,2)</sup>. As per the NCEPOD report, the number of children and young people reported to be receiving LTV in the UK increased from one in 1975 to almost 3,016 in 2018.

Guidelines and pathways for initiation of ventilation have been identified as important in the safe transition of these children from the intensive care unit/ high dependency unit setting to home <sup>(2)</sup>.

The scope of this guideline and pathway <u>(Control + click here to be redirected to NIV pathway</u>) is to provide a framework for initiation of long term non- invasive ventilation and safe discharge home as well as follow up after discharge. This guideline/ pathway applies to children on non-invasive ventilation only and not for tracheostomy ventilated children. There is a lack of validated criteria for CPAP/NIV initiation, optimal follow-up and monitoring, and weaning.

This guideline apply to patients on overnight respiratory support who are under LTV team

## 2. Definition and circumstances

A child who needs long-term ventilation (LTV) is "any child who, when medically stable, continues to require a mechanical aid for breathing, after an acknowledgedfailure to wean, or a slow wean, three months after institution of ventilation" <sup>(3)</sup>. Situations where LTV may be needed include airway obstruction, neuromuscular disease, pulmonary disease and disorders of respiratory control. The long-term management of children needing long term ventilation is summarized in the flow chart below (Figure 1, Ref 2).

Long-term noninvasive respiratory support consists of delivering a ventilatory assistance through a noninvasive interface, as opposed to invasive ventilation via an endotracheal tube or a tracheostomy. Noninvasive respiratory support comprises 1) continuous positive airway pressure (CPAP) which is based on the delivery of a constant positive pressure in the airways aiming to maintain airway patency and, 2) noninvasive ventilation (NIV) *per se* (or bilevel positive airway pressure, BiPAP) which aims to assist the breathing of the patient by delivering a supplemental higher positive pressure during each inspiration

Title: Initiation of long term non invasive ventilation V: 5 Approved by Children's Clinical Practice Group on: August 2022 Trust Ref: C37/2016 Next Review: August 2025 Page 2 of 16



#### Figure 1: Pathway of care -

Scope of this pathway (Flow chart adapted fromWest Midlands Quality Review Service <sup>(2)</sup>)

These children may have different levels of need (Table 1, Ref<sup>2</sup>). Long term non-invasive ventilation (NIV) is suitable for children with high (Level 1) and some children with severe (Level 2) levels of need, but not suitable for children with priority (level 3) level of need. This pathway deals with the initiation of long-term NIV and safe discharge home (bold text in Figure 1).

#### Table 1: Levels of need of children initiated on LTV

(Flow chart adapted from West Midlands Quality Review Service <sup>(2)</sup>)

High (Level 1)	Child is able to breathe unaided during the day but needs to go onto a ventilator for supportive ventilation. The ventilation can be discontinued for up to 24 hours without clinical harm
Severe (Level 2)	Child requires ventilation at night for very poor respiratory function; has respiratory drive and would survive accidental disconnection, but would be unwell and may require hospital support
Priority (Level 3)	Child has no respiratory drive at all and is dependent on ventilation at all times Child has no respiratory drive when asleep or unconscious who requireventilation and one-to-one support while asleep, and disconnection would be fatal

## 3. Suitability:

Decision regarding suitability for home NIV should be taken after clear discussion and documentation of the indication and long-term goals for the therapy. This should ideally be done in a multidisciplinary setting including respiratory consultants, palliative consultant and other specialty consultants where necessary.

Respiratory failure is common in children with terminal illness. CPAP/NIV is sometimes an alternative to invasive ventilation when it is not indicated/appropriate due to disease progression. Within this context, CPAP/NIV may contribute to symptom control and improvement in QoL.<sup>7</sup>

A stable airway is a prerequisite for NIV

#### **Relative contraindications to NIV**

- Multiple failed extubation attempts
- Dependence on mask NIV for >16hr/ day
- Inability to protect the upper airways due to bulbar dysfunction and/or copious respiratory secretions,
- Lack of cooperation of the patient and/or the family,
- Uncontrolled severe gastro-esophageal reflux or severe aerophagia
- High ventilator dependence
- Depending on individual cases: Anatomical facial abnormalities,
- Recent facial surgery or complications related to the interface

In most situations, duration of NIV should not exceed 14-16 hours per day, especially in younger children due to midfacial hypoplasia and mask pressure related ulcers with longer duration of mask ventilation<sup>(5)</sup>, however there may be exceptions. Similarly, peak pressures >20 cm H2O are not generally suitable for NIV because of problems with leaks and aerophagia<sup>(6)</sup>, however there may be exceptions.

It is important to exclude co-morbidities, especially reflux disease. If there is recurrent vomiting, excessive secretions or reflux not controlled by medical therapy these need to be addressed before initiating NIV.

## 4. Preparation of the family and Child:

Prior to setting up NIV in a child, parents and children (where able) should have a clear understanding of the indications and potential benefits of NIV (e.g., improved function, prolongation of life etc.). Detailed discussion should be held and documented as informed consent explaining the risks (e.g., mask pressure sores, risk of mid face hypoplasia in younger children, risk of aspiration and effect of dislodgement or leak around mask interfaces), expected duration of stay and training needed as a minimum.

#### 5. Initiation:

Initiation of NIV in children requires a clinical decision to be made regarding the mode and settings of ventilation and the interface (mask, nasal prong etc.). These decisions are ideally done in a multi-disciplinary setting with respiratory consultant, respiratory nurse, and respiratory physiologist/ technician.

#### Location of initiation of NIV

- In an acute/subacute (pediatric intensive care unit (PICU) or HDU) setting
- Electively (in a stable setting, after a sleep study) in outpatients/home
- Electively in hospital settings in ward 12

#### Initial settings of NIV

The initial ventilator settingmay be kept at low levels to allow the child to adjust to the mask and flow. The settings can then be increased slowly over next 2-3 days to optimum levels depending on the tolerance of the child.

The settings should clearly be documented in patient's ventilator prescription and kept in nursing folder.

#### Home initiation of NIV

At the discretion of the LTV team, occasionally it is deemed appropriate for patients to be setup on NIV at home.

- Patients attend Paediatric Respiratory Physiology Laboratory.
- Senior Physiologist would review appropriateness of different interfaces and then along with patient and parent/guardian select the desired interface.
- Patient trailed on ventilation whilst awake, minimal ventilation settings started with and titrated as tolerated.
- Training provided to patient (if appropriate) and parent/guardian.
- Patient sent home to establish on ventilation.
- Telephone call follows ups as appropriate, initially every few days to monitor compliance.
- Once compliant, overnight Oxycapnography as a minimum to assess pressures and then pressures titrated accordingly.

## 6. Equipment

#### > Selection of interface

An appropriately fitting mask interface plays a vital role in the success and quality of NIV. The aim is to achieve compromise between different aspects including reducing leak, patient comfort and ease of application. A variety of differentfactory-made masks of different design, shape, size, color and materials are nowavailable which range from infants to adult sizes. The importance of an appropriately fitted headgear should not be underestimated, especially in children with skull or cranial deformity

Trial of different masks shouldbe done by respiratory physiologists or respiratory/ward nurses in the initiation period and later in the follow up period with growth of the child as necessary. For children who need day and night ventilation or long periods of ventilation per day should be provided with a selection of masks, at least two that fit the face to alternate to reduce the likelihood of pressure sores.

Different types of interfaces include the following:

- 1. Nasal masks: cover just the nostrils/nose: should be the preferred choice
- 2. Nasal Pillow: saddle the nostrils
- 3. Full face mask: cover the mouth and nose

- 4. Total face mask: run around the rim of the face
- 5. Mouth piece: mainly for adjunctive day time ventilation in patients with neuromuscular disorders who are unable to maintain day time carbon di oxide levels in normal range and require support in day time in addition to night

#### > Ventilator (new)

The choice of device is based on the child's characteristics (weight, underlying disease, and ability to trigger the ventilator) and medical needs (clinical stability).

Ventilators used in our hospital

- Astral ResMed: minimum weight 5kg
- Nippy Junior: no new initiation on Nippy
- Stella ResMed: minimum weight 13kg

Humidification of inspired air seems associated with a greater comfort and less secretions problems.

As NIV airflow transitions through usual channels of humidification of air, i.e. nose, children with NIV do not necessarily require humidification. However, due consideration should be given to the fact that the flow of air may be too high for humidification system to become overwhelmed leading to patient discomfort and lack of tolerance. Initial trials may be done with non-humidified flow or children moved on to non-humidified flow as per physician discretion mainly in stable children who can tolerate this well and do not have excessive drying of secretions with non-humidified flow.

All children <1 yr  $\longrightarrow$  to start with humidification >1yr  $\longrightarrow$  dry circuit to start and then monitor

#### Alarms

All Astral ventilators should have 3 minimum alarms – disconnection, apnea and leak. Alarm setting set as per vent manual

Stella- there is no disconnection alarm

Oxygen set up at home is done as per clinical needs of individual child. Oxygen saturation monitoring at home is not routinely provided. Prior to discharge the monitoring in the hospital should be reduced to allow building parents confidence.

#### Saturation monitoring at home to be considered in children

- 1. Age < 6 years
- 2. Full face or total face mask
- 3. Children with Level 2 need (as per table 1)
- 4. Children deemed to be without mental capacity to remove mask by themselves

#### Child with level 1 need:

- One ventilator in the home
- Access to a replacement ventilator within 24 hours

#### Child with (level 2 or 3):

- Two ventilators including internal and external battery backup
- Arrangement to replace saturation monitor within 12 hours depending on level of care child needs

## 7. Progress and monitoring:

The progress of the child on NIV is monitored, with particular attention being given to intercurrent problems including leaks, pressure sores and non- acceptance of the interface by the child. Other interfaces may need to be tried. Perseverance is often the key, because children tend to get used to the interface.

Once the patient has tolerated the ventilator well for 48-72hr than the NIV discharge pathway should be started.

## 8. Discharge Planning

#### > Ventilator parameters for home and transition to home equipment

Once the interface is tolerated and problem free, adequacy of ventilation is assessed by various measures including oximetry, transcutaneous carbon dioxidemeasurement, blood gases and bed side assessments which help determine appropriate ventilator settings and allow maximum possible time off the ventilator in a 24-hour period. In a newly initiated patient, a minimum of 8 hours off the ventilator in day time is required prior to discharge.

Prior to discharge all children should have overnight oximetry and assessment of CO2 levels as a minimum and a sleep study should be considered where necessary.

Early set up of home equipment will allow time for identifying challenges and will facilitate adherence. Prior to discharge home, children should be changed to home equipment including home ventilator where possible. Approval of home equipment is necessary prior to discharge

#### Training of parents and careers

- Training of an adult career is essential prior to discharge. Therapeutic education of the caregivers and the patient is of paramount importance, as well as continuous support and assistance, in order to achieve optimal adherence.
- This includes training to use the equipment (ventilator, mask, humidifier, suction equipment, saturation monitor etc.) and to identify and troubleshoot common problems (including equipment alarms).
- Basic life support training is extended to all parents/ carers. It is also important to teach parents/ careers to identify exacerbations/inter-current illnessesin children and to develop a plan for escalation of treatment in case of intercurrent illnesses. Most children will need open access to the children's hospital.
- Ventilator training form should be used for documentation of training

Home oxygen set up may or may not be required based on clinical circumstances. The provision of home oxygen should be requested and instituted as necessary following discussion with respiratory team/consultant.

#### > Step down to local hospital where applicable

Communication is especially important for children not from the region (i.e., LLR), in which case consideration must be given to step down to a local DGH prior to discharge. The local hospital pediatric team and community pediatric team needs to be notified of the diagnosis and management. A pre-discharge MDT is necessary in most cases. Parents, professionals from different specialties involved and community team should be invited as

Title: Initiation of long term noninvasive ventilation V:4 Approved by Children's Clinical Practice Group on: August 2022 Trust Ref: C37/2016 Next Review: August 2025

necessary.

A child on the LTV integrated care pathway must have an identified lead Consultant locally as well as at LRI who will provide consistent communication around the needs of the child and family and ensure that the medical aspects of the child's care are being met, and that these have been considered and communicated as part of the risk assessment for transfer of care closer to home. Communication between hospital and community providers is essential in order to maintain objectives and a structured process of sharing information in the interests of the child is essential.

The keys to successful discharge include communication, training and planning for emergencies.

Referral to community physiotherapy team should be considered as necessary. Ideally a community key worker from community nursing team should be identified for every child.

#### Documentation for discharge

- 1. A ventilator prescription clearly outlining ventilator setting at discharge (including sick day settings when child is unwell and need increase in pressures which can be done by community team, applicable in selected cases only as per physician discretion)
- 2. A Respiratory exacerbation plan providing basic guidance for management of respiratory illness and contact details of respiratory team.
- 3. RESPECT form where applicable
- 4. Discharge letter should be copied to various professionals involved including DGH consultants.

The discharge paperwork should be discussed with parents/carers before discharge. As a general guidance, discharge date should be planned in advance and depending on resources should be aimed to be kept earlier in the weekdays rather than over on Friday/weekends/bank holidays so that parents can access community/respiratory team support in their initial few days home.

## 9. Follow up:

Several studies showed the persistence of respiratory events and/or abnormal nocturnal gas exchange requiring an intervention during systematic follow up sleep studies performed 3 to 6 months after CPAP/NIV initiation, even in asymptomatic patients.<sup>7)</sup>

- Follow up with community nursing team should be arranged as soon as possible in the first few days following discharge.
- Follow up with respiratory physiologist shouldbe organized if necessary for review of progress
- Regular visits every 3 to 6 months are usually considered as a minimum <sup>7</sup>.
- A follow up sleep study to check CPAP/NIV settings is useful after each intervention (e.g., change in ventilator settings, upper airway or maxillofacial surgery, orthodontics) that may affect the severity of SDB.
- Overnight studies including oximetry, capnography should be conducted on annual or biannual basis as necessary to assess adequacy of ventilation. Consideration for sleep study shouldbe given where required.
- Ventilator prescription, health care plan, escalation plans and advance care plans all need to be kept up to date and reviewed when there is a change in the child's circumstances, and not less frequently than annually. This should be completed by the LTV nurse and community-based key worker

Title: Initiation of long term noninvasive ventilation V:4 Approved by Children's Clinical Practice Group on: August 2022 Trust Ref: C37/2016 Next Review: August 2025

#### Compliance

Poor adherence represents one of the most important challenges for long term CPAP/NIV. Although there is no validated definition of good/optimal adherence in children, optimal adherence is a priority: the use of CPAP/NIV during the entire sleep time is the goal. Adherence is usually evaluated regularly based on objective data (built-in software data). Numerous factors related to the patient and the family may impact adherence. Individually adapted strategies may improve adherence.

#### Weaning<sup>7</sup>

6 to 40% of children can be weaned from long term CPAP or NIV. Weaning may be possible due to spontaneous improvement with age (physiological growth) or after an intervention After successful weaning, recurrence of SDB or hypoventilation may occur, underlining the need for continued follow up, at least clinically, depending on the underlying condition as per physician discretion.

#### Pathway:

The pathway in the appendices is a checklist to ensure that these steps are undertaken prior to discharge of children on long term NIV. The pages are designed to be printed out and used with each child, ideally to be placed in the front of the nursing notes. The pathway should be completed as a team, jointly by respiratory registrars (or consultants where necessary), respiratory nurse specialists and named nurses on ward or ward nurseslooking after the child as necessary.

#### **Education and Training**

None

## **Monitoring Compliance**

What will be measuredto monitor compliance	How will compliancebe monitored	Monitoring Lead	Frequency	Reporting arrangements
Compliance withpathway for all children initiated on NIV	Audit	LTV service lead	yearly	
Clinical incidents, complaints, morbidity and/or mortality in children initiated on NIV	Datix forms,complaints, serious case reviews	Clinical Governance lead for CMG.	Accordingto trust policy	

Title: Initiation of long term noninvasive ventilation

V:4 Approved by Children's Clinical Practice Group on: August 2022 Trust Ref: C37/2016 Next Review: August 2025

## **Supporting References**

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- 6. Han YJ et al. Home mechanical ventilation in childhood-onset hereditary neuromuscular disease: 13 years experience at a single center in Korea.Plos one 10(3): e0122346
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- 8. NCEPOD

## Key Words

Long term ventilation, non-invasive ventilation, ventilation in children, home ventilation

The Trust recognizes the diversity of the local community it serves. Our aim therefore is to provide a safe environment free from discrimination and treat all individuals fairly with dignityand appropriately according to their needs. As part of its development, this policy and its impact on equality have been reviewed and nodetriment was identified.

CONTACT AND REVIEW DETAILS	
Guideline Lead (Name and Title) Dr Tahera Doctor - Locum Consultant in Pediatric respiratory medicine	Executive Lead Chief Nurse
Details of Changes made during review: Introduction – statistics added Added paragraph regarding suitability Initiation section reformatted Equipment section added humidification advice moved in equipment section Discharge planning section updated Follow up section updated with addition of weaning Re-format throughout References updated NIV initiation pathway in appendix changed to discl Added ventilation prescription, sleep study referrat checklist to appendix	harge pathway I & ventilator training

# Pathway for discharge of long-term

## non-invasive ventilation in children



Caring at its best

Insert Patient Sticker	

### 1. Entrance to pathway

Needs long term ventilator support/ nocturnal ventilator support Yes 🗆 Parents' informed consent to initiating long term NIV support Yes 🗆		
Staff member signature/ Name:	_/ Dated:	
2. Admission checklists - appropriateness for NIV:		
Level of support (see appendix 1):	Level 1 🗆, Level 2 🗆, Level 3 🗆	
Appropriate for NIV: Yes 🗆	MDT date:	

#### 3. Final NIV settings

Interface		Final Ventilation Settings		
1. Total face mask:		1. Ventilator		
<ol><li>Full face mask – type:</li></ol>		2. Mode		
3. Nasal mask – type:		3. Pressures – IPAP/EPAPcm $H_2O$		
4. Nasal pillow – type:		4. Ti BUR		
5. Nasal prong:		5. Oxygen/Air		
6. Other:		6. Trigger settings:		
		<ol><li>Duration/ Time off in day:hrs</li></ol>		

#### 4. Investigation checklists:

i. Aspiration (SALT assessment):

Needed  $\Box$  Not Needed  $\Box$ :

Swallowing - safe □/ Unsafe□

If deemed unsafe swallow - alternative modes of feeding – asogastric tube / PEG / any other mode Any other comments:

 ii. Reflux disease: Yes □ No □ possible □: pH study □/ Barium swallow□/ impedance study □
 Comments:

 Title: Initiation of long term noninvasive ventilation

 V:4
 Approved by Children's Clinical Practice Group on: August 2022

 Trust Ref: C37/2016
 Next Review: August 2025

- iii. Final oximetry/ sleep study/ O2-CO<sub>2</sub> study pre-discharge date: Results:
- iv. Other investigations:

Staff member signature/ Name:	Dated:

#### 5. Discharge Check list

- 1. Communication with community team:  $\Box$
- 2. Consider immunization (e.g. RSV prophylaxis/ seasonal influenza/ Covid-19, other relevant): □ (if applicable)
- 3. MDT:
  - a. 🛛 Identify Lead Consultant : \_\_\_\_\_
  - b. 🛛 Identify clinical lead (local hospital/ community): Named local clinical lead informed \_\_\_\_\_\_
  - c. Does the child need a referral for continuing healthcare funding? : \_\_\_\_\_
  - d. Out of county : consider transfer to local hospital before discharge home:\_\_\_\_
- 4. Equipment checks as applicable: (include, if appropriate, model name/ serial number/ date checked/ date next check due)
  - a. 🛛 Ventilator/ CPAP machine: \_\_\_\_\_\_
  - b. 🛛 Humidifier : \_\_\_\_\_
  - c. 🛛 Oxygen: \_\_\_\_

  - e. 🛛 Suction machine :
  - f. 🛛 Accessories/ consumables: \_\_\_\_
  - g. Funding agreed for equipment from the relevant Clinical Commissioning Group (CCG):

- 5. Discharge document checklist
  - a. Discharge letter
    - b. Respiratory escalation
  - management plan (REM)
  - c. Ventilator Prescription
  - d. ReSPECT paperwork (where available)

#### 6. Parents training:

a.	BLS:
b.	Feeds – feeding pump:

- c. D NG tube checking / replacement:
- d. 
  Ventilator/ humidifier/ Sats monitor
- e. 
  D Oxygen training
- f. 🛛 Suction unit
  - Follow up sleep study requested to
  - physiologist\_\_\_\_\_(month)
  - □ Next clinic review in \_\_\_\_\_(months)

Staff member signature/ Name:\_\_\_\_\_/\_\_\_\_

V:4 Approved by Children's Clinical Practice Group on: August 2022 Trust Ref: C37/2016 Next Review: August 2025

## SLEEP STUDY (POLYGRAPHY) REFERRALS

Date of referral:	//				
Referral request:	Polygraphy (full sleep study) Polygraphy WITH capnograp Overnight oximetry	ohy	[ [ ]	] ] ]	Select appropriate
REFERRING CLI	NICIAN				
NAME					
DESIGNATION:					
DEPARTMENT:					
HOSPITAL:					
Consultant in cha	rge				
Has the referral b	een approved by consultant?		١	/es [	] No [ ]
PATIENT DETAIL	<u>_S</u>				
NAME:					
HOSPITAL NUM	BER:				
DATE OF BIRTH	:				
DIAGNOSES:					
IMPORTANT CL	INICAL FINDINGS ( <u>must</u> ir	lud	e E	NT e	examination where OSA
considered)					
REASON FOR R	EFERRAL Why are you	requ	uest	ing a	sleep study?
Has this child had	a PSG or overnight oximetry	/ befo	ore?		Yes [ ]
No [	]				
If yes, what is the	reason for re-referral?				
Please ensu	re form is complete. Incon	nplet	e re	ques	sts will be returned.

Checklist (Sleep service ONLY) (select appropriate study):

1. <u>OSA referrals:</u> Basic Polygraphy (Flow, Respiratory effort including RIPsum, Saturations, Heart rate, Actigraphy from Somno unit)

2. <u>Nocturnal hypoventilation:</u> Polygraphy with Capnography (Flow, Respiratory effort including RIPsum, Saturations, Heart rate, Actigraphy from unit, Capnography via TCM5).



#### **Ventilation Prescription**

Name:	
Hospital Number:	
Date of Birth:	
Consultant:	
Date:	

#### **Clinical Settings**

Mode	IPAP (cmH2O)	EPAP (cmH2O)
T: Mire		
	11 Max	васк-ир кк
(secs)	(secs)	(ВРМ)
Trigger	Cycle	Rise Time
		(msecs)

#### **Circuit Settings**

Circuit Type	
Patient Interface	
Mask Type	

#### **Alarm Settings**

Low Min Vent	High Leak	
Non-Vented Mask	High Pressure	
Low Pressure	High Resp Rate	
Low Resp Rate	Apnea Alarm	
Alarm Volume		

Signature: Date:

Designation:

Confirmed By: Signature:

Designation:

#### Any queries please do not hesitate to contact The Children's LTV Team.

Children's LTV Team C/O ward 28 Leicester Royal Infirmary Tel 0116 258 6694

Title: Initiation of long term noninvasive ventilation V:4 Approved by Children's Clinical Practice Group on: August 2022 Trust Ref: C37/2016 Next Review: August 2025

Page 14 of 15



#### University Hospitals of Leicester Trust Children's Hospital

#### Ventilator Training Checklist

#### Name of Child/Young Person:

.....

## Printed Name of Parent/Guardian:

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## Name of Ventilator:

.....

This competency checklist is designed to complete with parents/guardians prior to discharge to ensure they have sufficient knowledge of how to use the ventilator to care for their child/young person at home when using this device.

Competency to complete

I understand how to connect to mains power and know how to determine if using mains or battery power.		
I am able to power the ventilator on and off.		
I am correctly fit mask and check for any excessive mask leak		
I am able to turn the ventilator on to deliver ventilation pressures.		
I understand where to check the ventilator is delivering the correct pressure.		
I understand where to look to check the ventilator settings against ventilator prescription.		
I understand what to do if these settings differ from ventilator prescription.		
I am aware of the alarms that are set and what they mean.		
Aware of how to respond to the alarms set on the ventilator.		
I know who to contact if we have continued problems with alarm settings.		
I am able to mute and unmute alarm and risks of leaving alarm muted.		
(If O2 requirement) I am able to attach ventilator to Oxygen supply.		
(If O2 requirement) I am aware of how much oxygen my child should receive overnight.		
I know who to contact for ongoing consumables (masks, circuits etc)		
I have been explained signs of pressure sores and what to do if I think one is developing.		
I understand how to assemble wet ventilator circuit. (If required)		
I understand how to assemble dry ventilator circuit. ( <i>if required</i> )		
I am able to correctly learn circuit.		
I understand how to clean mask and when to change circuit.		
I understand to only use distilled water for humidifier.		
I know that humidifier should always be placed below the ventilator.		
(Astral only) I have been explained about 24 hour service cover package.		

Signed by parent/guardian:

.....

Signed by competent assessor:

.....

#### Print competent assessor name:

.....

Tick