

Pan Thames Paediatric LTV Programme



**North Thames
Paediatric Network**
Connecting paediatric services



**South Thames
Paediatric Network**
Transforming Healthcare for
Children and Young People

Pan Thames Paediatric LTV Programme

Cold Weather, Warm Care: Winter Support for Paediatric LTV in the Community

September 2025



Prologue

Pan Thames Paediatric Long-Term Ventilation (LTV) Programme.

Since the winter of 2023, the provision of long-term ventilation (LTV) services across the South Thames Paediatric Network (STPN) and North Thames Paediatric Network (NTPN) has undergone substantial and strategic transformation. The Pan Thames Paediatric LTV Programme was commissioned to lead this initiative change, with the aim of improving care delivered to babies, children, and young people requiring tracheostomy (Tr LTV) or non-invasive ventilation (NIV).

Our mission is to

- Act as an interface between health care professionals and commissioners.
- Address systemic barriers to timely discharge and transfer of care.
- Prevent avoidable readmissions and support efficient use of resources.

We are a dedicated multi-disciplinary team working collaboratively to deliver this vision.

The Pan Thames LTV Programme covers a wide geographical area, including:

- London
- Kent
- Medway
- Surrey Heartlands
- Sussex
- Bordering areas of the East of England

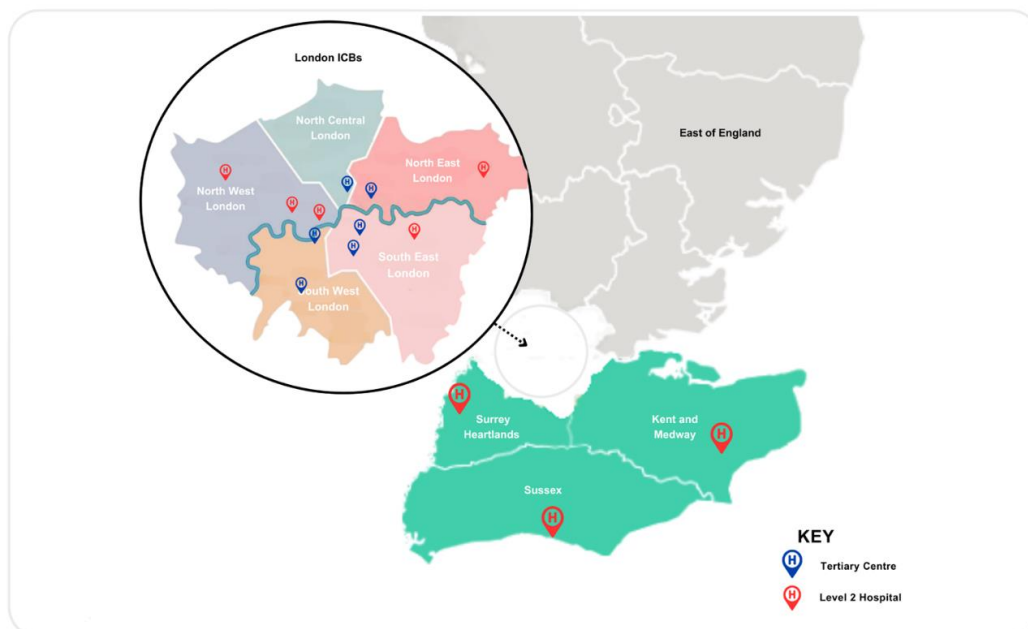


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Document History

Date of revision	Version Number	Author(s)	Reason for update review
September 2025	V.1	Alice Francis	New document

1. Introduction

This ‘Cold Weather Warm Care’ support document has been developed to assist community healthcare professionals in delivering safe, coordinated and proactive care for babies, children, and young people (BCYP) requiring LTV across the Pan Thames Paediatric Programme region.

“Long-term ventilation (LTV) refers to various types of respiratory support provided every day for a period of at least three months. Ventilation is delivered either via a tracheostomy tube (invasive) or via a face mask or nasal cannula (non-invasive).

The aim of LTV is to improve survival and quality of life in people with conditions that have led to respiratory failure.”
NCPOD, 2020¹³

For the purposes of this document community teams include children’s community nursing teams, GP’s, health visitors, community paediatricians and school nurses.

BCYP with complex respiratory needs are especially vulnerable during the winter months, when seasonal illness, environmental changes, and service pressures can impact their health and wellbeing. This guide aims to support professionals working in community settings by providing clear, practical information on winter preparedness, useful resources, escalation planning, equipment management, and collaborative working across services.

In alignment with the NHS Long Term Plan, this document also recognises the significant impact of social determinants on health outcomes. Factors such as financial insecurity, housing instability, and mental health challenges can exacerbate the risks faced by families caring for children on LTV. To address these broader needs, this guide includes resources to support families in accessing financial assistance and grants, mental health services, and housing support. By integrating these elements into care planning, we aim to promote equity, reduce avoidable admissions, and empower families to feel confident and well-supported at home.

By strengthening communication and consistency across the region, we can help ensure that every BCYP on LTV receives timely, high-quality, and holistic care.

2. Winter Health Risk and Respiratory Considerations

During the winter months (typically peaking between November and February), Paediatric Critical Care services experience a significant surge in demand for respiratory illnesses¹¹. This is particularly important for our LTV population, as they generally require a Paediatric Critical Care bed of some level when acutely unwell and require hospital admission. Without proactive winter planning, BCYP on LTV are at higher risk of unplanned hospital admissions, which can have an impact on acute services⁹, and can be distressing for the child and their family, and disruptive to the continuity of their care. These admissions can also place a significant financial strain on families, who may face unexpected expenses such as travel, food, and childcare, alongside the potential loss of income due to time taken off work.

2.1 Winter Risks

A key risk during unplanned admissions is the breakdown of care packages, especially when there is no hospital admission protocol (HAP) or equivalent arrangement in place that enables the home care team to continue supporting the child in hospital¹. Many home care staff are employed on zero-hour contracts, and if they are not actively engaged during a hospital stay, they may be reassigned to other care packages or seek alternative work. This can result in a lack of available staff when the child is ready for discharge, delaying their return home and placing additional pressure on inpatient services. For further information regarding the HAP please email our team, gstt.panthamesltv@nhs.net.

BCYP on LTV should be up to date with the recommended childhood vaccinations⁹. BCYP requiring LTV and those with underlying respiratory conditions are more susceptible to seasonal infections such as RSV, influenza, COVID-19, and rhinovirus. These infections can lead to rapid deterioration, requiring increased support and hospital admission. The Pan Thames LTV Programme recommends that community services actively promote the early uptake of annual vaccinations for BCYP on LTV, as well as for their caregivers. This includes vaccines such as the seasonal influenza vaccine and RSV prophylaxis; actions should be based on the current JCVI recommendations. It is vital that community vaccination teams and GP practices are informed about and prioritise children on LTV, ensuring timely access to these essential preventative interventions.



2.2 Why does cold weather matter?

In an Asthma + Lung UK survey, 7 in 10 people said that the cold air made their lung condition symptoms worse². This could be due to several reasons, the cold air can cause airways to narrow, making it more difficult to breathe and increasing mucus production.

The dry, chilly air can also irritate airways, worsening symptoms like wheezing, coughing, and shortness of breath. Wintry weather may weaken the immune system, reducing the ability to fight off respiratory infections such as colds and flu.

Additionally, we tend to spend more time indoors during colder months, often in close contact with others, which makes it much easier for viruses to spread².

Moving between cold outdoor environments and heated indoor spaces can be particularly drying and irritating to the airways. Sudden temperature changes can trigger bronchospasm and exacerbate symptoms in children with chronic respiratory conditions⁷. This is due to rapid evaporation of airway surface fluid and increased airway hyperresponsiveness. For children with complex respiratory needs, it may be beneficial to consider an additional nebuliser treatment during these transitions to help maintain airway hydration and reduce the risk of symptom escalation⁸.

3. Home Environment & Equipment Readiness

Creating a safe and healthy home environment is essential for managing any respiratory condition, especially for those who are young and on LTV. This section offers practical tips to help reduce common indoor triggers like damp, mould, and poor air quality, whilst also highlighting the importance of keeping essential equipment ready and in good working order. Ensuring that a BYCP and family have appropriate arrangements in place at home to maintain a safe and stable environment is key in reducing the risk of admission⁹.

3.1 Indoor Air Quality & Temperature

Encouraging families and carers to ventilate the home for short periods each day can help reduce condensation and improve indoor air quality³. Short bursts of fresh air can make a significant difference without significantly lowering indoor temperatures. If the home has damp, it is important to address it, especially if there is visible mould, as this can be particularly harmful for people with lung conditions. Damp and mouldy environments can worsen respiratory symptoms and increase the risk of infections^{2 3}.

For further resources, you can signpost families to our website: [Damp & Mould Advice for patients - Pan Thames Paediatric Long Term Ventilation Network](#)

Complementing the family resource, the following material is designed for

professionals [Damp and mould - Pan Thames Paediatric Long Term Ventilation Network](#)

During the winter months, it is recommended that indoor temperatures be maintained between 18°C and 21°C to support health and comfort ^{2,4}. Homes with individuals who have reduced mobility may need to keep the home slightly warmer². For infants the guidance remains the same as that from The Lullaby Trust: the room for sleeping, temperature should be kept between 16°C and 20°C (61–68°F) to help reduce the risk of sudden infant death syndrome (SIDS)⁵.

3.2 Power Supply and Preparedness for Ventilator-Dependent Children

The risk of widespread power cuts in the UK this winter is currently considered very low⁶, however, localised outages can still happen due to severe weather or technical faults. Community teams supporting BCYP who are on LTV should ensure that families have registered with their local energy provider's Priority Services Register (PSR). This has often been done prior to their original discharge. This is a free service that offers critical support during power outages, including advance notice of planned cuts, priority reconnection, and access to emergency assistance. As part of ongoing care, teams should check that registration has been completed and provide guidance if needed, to help safeguard the child's health and ensure continuity of care in the home environment.

[The PSR - The Priority Services Register \(PSR\) is a free UK wide service which provides extra advice and support, including when there's an interruption to your electricity or gas supply - PSR](#)

Not all ventilators come with a built-in battery. Whether a ventilator includes an internal battery, an external battery, or both will be determined by the level of reliance the BCYP has on ventilatory support. If the BCYP has two devices or external batteries this can be used as a general guidance on how reliant they are on the ventilator⁹ a second ventilator may also be issued to those living in a remote location⁹. Family's and carers are recommended to rotate use of the devices and external batteries to ensure they are in good working order, they should never be used as a backup device and stored in a cupboard.

Please see below for a quick guide to ventilator battery run time on the most common seen ventilators in our region. Please note that many factors can affect battery efficiency, including environmental temperature, the ventilator settings, the age and condition of the battery, additional equipment attached to the ventilator (i.e.



nebulisers), and usage duration. Always refer to the manufacturer's guidance for full and up-to-date details on battery performance and safety recommendations.

Ventilator		Approximate Internal Battery Run time	Additional battery	Notes
ResMed:	Astral 100/150	8 hours	External battery adds 8 hours	Up to 2 external batteries can be used for 24 hours total
	Stellar	3 hours	ResMed Power station- 8h approx.	
	Lumis 100/150	No internal battery	ResMed Power station- 8-13h approx.	
	Airsense 10/11	No internal battery	AS 10- ResMed Power station 8-13h approx.	
Breas:	Nippy Junior+	4 hours+		Battery run times are dependent on the ventilator settings and the amount of leak. The expected run time can be displayed on screen. Double press the SET button to display a bar graph of run time.
	Nippy 4	2.5 hours	6.5 hrs Click in battery	
	Nippy 4+	2.5 hours	6.5 hrs Click in battery	
Philips	Trilogy 100	4 hours	4hrs - Detachable battery	
	Trilogy Evo	7.5hs	7.5hs detachable battery	
*Information obtained from manufacture guidance when battery is new				

Ensuring reliable access to power is essential for children who rely on ventilators and other life-sustaining equipment. Good practice is to monitor battery level; this is especially important during the winter months when travel delays and disruptions are more likely. Those in the community should take every opportunity to recharge equipment. GP practices & community clinics should ensure there is an accessible power socket for device charging while waiting. Schools and education settings can ensure adequate battery charge by giving opportunities during stationary periods at school to plug in essential devices. This planning for the possibility of a delayed journey home and ensuring that all devices are adequately charged before leaving, can help prevent avoidable emergencies and support continuity of care.

3.3 Equipment, supplies, and maintenance checks

It is essential to ensure an adequate supply of consumables are always available, and that local teams are familiar with the processes for obtaining LTV equipment, particularly during out of hours or in urgent situations e.g. in case of ventilator failure. Procedures for accessing ventilation equipment may vary depending on the child's tertiary centre, servicing contracts, and local commissioning arrangements. Therefore, teams must be aware of the correct escalation routes and contact points relevant for that BCYP. This information, including the contact details for the LTV centre is often available in the respiratory action plan/ equivalent document

Families and carers are provided this information prior to discharge and may contact the LTV service directly if needed. However, if they have never had to use these procedures, it is possible they may have forgotten the details. Community teams should be prepared to support families in navigating these processes and ensure that information is readily accessible when needed.

Key considerations:

Consumable Management: while teams are encouraged to be mindful of the use of resources & avoid over stocking. They should also be aware that the demand for certain equipment may increase with seasonal illness, for instance suction catheters, and nebuliser solution such as 0.9% Sodium Chloride.

Reporting of supply issues: Any new ongoing difficulties in ordering consumables, should ideally be reported to the BCYP tertiary centre alongside emailing The Pan Thames Paediatric LTV programme (gstt.panthamesltv@nhs.net), this is so the team can identify if it's a wider issue and to support in resolving. An example of this is the ongoing nationwide issue with sterile water for inhalation, where the team has collaborated with multiple national NHS teams to address the issue and develop innovative solutions.

3.4 Cost of utilities

During the colder months, some families of BCYP on LTV may experience increased anxiety around the rising cost of utilities, particularly due to the need for continuous use of medical equipment such as ventilators and suction machines. These concerns can add to the emotional and financial pressures already faced by families managing complex care at home. It is important for community healthcare professionals to be aware of these challenges and to signpost families to available support.

[Section 7:](#) of this document outlines key resources and services that may help alleviate financial strain, including information on energy cost assistance, welfare benefits, and charitable grants.

4. Emergency Preparedness Clinical Decision Making in Winter

Supporting BCYP on LTV in the community requires proactive planning and informed clinical judgement, particularly during an acute illness or in emergency situations. This section outlines key considerations for ensuring safety and continuity of care during the acutely unwell episode. It also explains the role of a Respiratory Action Plan (RAP) or equivalent document, including what this is and the information you can expect to find within it.

4.1 Respiratory Action plan or equivalent document

BCYP receiving LTV will have a home support document and an escalation plan in place. This may be in the form of a Respiratory Action Plan (RAP) or another equivalent format. A RAP is a personalised, written plan developed by the BCYP LTV team to guide families, carers, and professionals in recognising and responding to changes in the child's respiratory health. It outlines specific actions to take during periods of deterioration or emergency, helping ensure timely and appropriate care in the community setting. The parents and carers of the BCYP should be enabled to escalate care to the limits of the RAP. They will then inform appropriate teams to gain further advice. The BCYP must be physically assessed by a clinical team, in the community this may be the GP or community nursing team, this assessment could include taking specimens and prescribing additional medications as needed⁹. It is best practice to ensure timely communication with the BCYP's LTV team regarding the clinical findings.

Click the link to watch a short video explaining the Respiratory Action Plan [Pan Thames RAP HCP video](#)

In a RAP or equivalent document, you will find the baseline information about that BCYP including their usual respiratory status, LTV and oxygen requirements (e.g. if they are only nocturnal ventilated), current ventilator prescription and if they have any additional setting such as unwell or a sick day protocol. This document will also outline individual signs of deterioration, which is especially important as condition depending, some may not present with typical symptoms, for example a child with Spinal Muscular Atrophy (SMA) may not increase their respiratory effort. This personalised insight complements clinical assessment skills.

While the Pan Thames RAP includes a traffic light escalation plan, not all documents currently use this format. However, they will have guidance on management of respiratory deterioration, this section may include recommended antibiotics, based on previous microbiology results and known colonisations (e.g. pseudomonas). Early interventions help to avoid admissions⁹. Additionally, the document will provide contact details for the relevant LTV team, location of usual hospital, any ambulance advanced directive and if the BCYP has an Advanced Care Plan in place. In any episode where the BCYP is unstable or very unwell they should be taken to their nearest A&E for stabilisation.

4.2 Strengthening Clinical Judgement Through Family/ Carer Insight

Clinical decision making in the community setting is enhanced by close collaboration with parents and carers, who hold vital knowledge about their BCYP baseline health and subtle changes that may indicate deterioration. As outlined in section 4.1, recognising early signs of being acutely unwell can be complex, particularly in those who cannot mount that respiratory response. These families have often spent extended periods in hospital and are highly attuned to their BCYP needs, and usually keen to avoid hospital admission unless necessary. Their insight is, therefore, essential in interpreting nuanced presentations along with using the RAP or equivalent document in ensuring prompt and appropriate responses.

4.3 Recognising Signs of Deterioration in All Skin Tones

Recognising early signs of illness in BCYP on LTV is critical, but it's important to acknowledge that some clinical signs, such as changes in skin colour, may present differently depending on the child's skin tone.

For example, cyanosis, which typically appears as a bluish tint in lighter skin, may present as grey, ashen, or dusky in children with darker skin. Areas such as the lips, tongue, gums, nail beds, palms, and soles should be assessed carefully. These signs may be subtle, so it is essential to combine visual assessment with other indicators

such as changes in breathing pattern, altered behaviour, temperature changes. Tools like the Bliss symptom spotter in darker skin tones¹² can support healthcare professionals in recognising these signs across diverse skin tones. However, clinical judgement, family insight, and familiarity with the child's baseline remain the most reliable tools for early identification and escalation.

5. Travel - safe travel with LTV equipment

Winter weather can present added challenges for children on long-term ventilation when travelling. It is important to plan to ensure journeys are safe, warm, and as smooth as possible as winter weather can increase the risk of travel delays.

Community teams can support by ensuring parents and carers are aware of:

- Checking weather forecast regularly and planning for icy or snowy conditions.
- Ensuring BCYP is appropriately dressed in layers, with particular attention to keeping the chest warm without obstructing ventilation equipment.
- During wet weather, ensure the ventilator is protected from rain and water splashes, especially when wheelchairs or pushchairs pass through puddles. Most home ventilators come with an optional travel bag.

NB: a home ventilator draws in air from the surrounding environment so while protecting devices is necessary it is also important to ensure that the air inlets are not occluded.

- Additional nebulisers may be required due to change in air temperatures going from cold outdoor to heated dry environment.
- Medical equipment should be secure but accessible if needed.
- For families planning longer car journeys, or who travel in areas known to have increased delays, and who's BCYP is dependent on ventilation, it may be helpful to consider purchasing a DC in-car adaptor to ensure the child's ventilator can be safely powered throughout the trip, further advice can be sought from the LTV centre.
- A dry, non- humidified circuit, should be used during travel. A humidified or wet circuit should never be used during travel, this is due to the risk of aspiration and to the electrical equipment, a humidifier is also mains powered.

Having a location-identifying app, such as What3Words, installed on a mobile device can be beneficial in the event of a breakdown or emergency, as it enables families and carers to accurately communicate their location to emergency services.

While the Pan Thames Paediatric LTV Programme acknowledges that there are no specific regulations covering the carriage of small quantities of medical gas in portable cylinders¹⁰, the following safety considerations are strongly recommended:

- Oxygen cylinders should never be in a patient's lap, at any time especially when traveling.
- They should be secured but accessible.
- Checks should be made to ensure enough oxygen is available for entire journey plus extra encase of delays
- Check for any obvious signs of leakage.
- Oxygen cylinders can carry an additional risk therefore families should notify their insurance company if traveling in their own vehicle, as failing to disclose could invalidate their insurance.
- There is no legal requirement to display a hazard sign when transporting small amounts of oxygen, but it is recommended to use signage to alert emergency services in case of an accident.
- Keep cylinders out of direct sunlight.
- Do not smoke near oxygen equipment, smoking in the vicinity of oxygen therapy creates a serious fire hazard and endangers everyone nearby.

6. School, and the journeys to and from

When a BCYP requires LTV support, careful planning is essential to ensure safety and continuity of care both in school and during transport.

Transport arrangements must be considered carefully: escorts should be familiar with BCYP needs including ventilator management and emergency procedures, and vehicles should be equipped to safely carry medical devices. For children who travel with portable oxygen or ventilators, coordination between families, schools, and transport providers is key to ensuring a safe and supportive environment.

Additionally, it is recommended those providing the transport to have a location-identifying app, such as What3Words, installed on a mobile device, apps such as these can provide a precise 3 meter squared location, which again can be beneficial in the event of a breakdown or emergency.

The vehicle heating also requires special attention. Heating systems in vehicles typically produce dry heat, which in colder months can contribute to the drying of airway secretions. This can increase the risk of airway obstruction or discomfort for BCYP. To mitigate this, some BCYP may require additional nebulisation prior to transportation or during the journey to help keep secretions loose and manageable.

Care plans should reflect this need, and escorts should be trained in administering nebulisers safely during transit if required.

Once at school, provisions must be made to ensure essential equipment, such as ventilators, can be charged during the day. Key staff should be appropriately trained in the operation of ventilators and emergency procedures. If the child requires LTV during school hours, a detailed care plan must be in place. For children who only need support when unwell, contingency plans should be established. Charging schedules should be coordinated around the child's individual needs and educational activities. In some settings, local risk assessments may be necessary to address potential hazards associated with charging equipment, such as trailing cables and the presence of other children.

CYP attending school who require ventilation during the school day are generally supported using their dry circuit. Those receiving ventilation via a tracheostomy often need regular nebulisers throughout the day to manage secretions. In more complex cases, some CYP may require time on a humidified (wet) circuit during school hours. In all instances, a thorough risk assessment must be carried out to ensure the safety of the child LTV and of others in the classroom. Where possible, the timing of interventions, such as nebulisation or switching to a wet circuit, should be planned around the child's educational activities to minimise disruption.

In addition, some CYP may require supplemental oxygen during the school day. Where this is the case, oxygen cylinders or concentrators must be stored safely on school premises, in accordance with relevant health and safety guidelines. The responsibility for safe storage and management of oxygen lies with the school, and appropriate insurance policies must be in place to cover its use and any associated risks.

7. Family and carer support

Caring for BCYP on LTV can be both rewarding and demanding, especially during the colder months, when health risk and logistical challenges increase. Families and carers play such a vital role in maintaining BCYP wellbeing, managing everyday responsibilities alongside complex care routines.

This section aims to emphasise the importance of supporting those who care for BCYP on LTV, recognising their expertise, emotional resilience and the need for practical, psychological and financial support. By ensuring families and carers are well informed, well equipped and well supported, we can help to reduce stress, prevent crisis, and promote continuity of care through winter and beyond.

For parents and carers concerned about energy costs, healthcare professionals can refer them to the Local Energy Advice Partnership (LEAP) this is a free service

designed to help families stay warm and reduce energy bills during the colder months. To refer a family, scan the QR code below or visit www.ltv.services/leap.



We also offer a range of resources for families on our website, including a [Winter Welfare Hub](#). This hub contains further information about available support. Healthcare professionals are encouraged to signpost families to these resources, many of which are suitable for children with complex care needs, not just those on LTV.

Mental Health and Winter Wellbeing

While the colder months can place additional emotional and practical strain on families caring for children with complex health needs. It's important to recognise and support their mental wellbeing.

Healthcare professionals can direct families to our dedicated Emotional and Practical Support page, which includes guidance on mental health, financial support, and coping strategies. These resources are designed to help families feel more supported and resilient during challenging times.

[Emotional and practical support - Pan Thames Paediatric Long Term Ventilation Network](#)

8. Resources

All the links below can be found on www.LTV.services website

8.1 Clinical

LTV clinical guideline [Clinical Guidance and Toolkit - Pan Thames Paediatric Long Term Ventilation Network](#)

LTV Hub Poster - [LTV resources/videos - Pan Thames Paediatric Long Term Ventilation Network](#)

Bliss winter illnesses [Symptom spotting on darker skin tones | Bliss](#)

8.2 Welfare

Welfare Hub poster [Welfare QR code hub \(Poster\)](#)

Winter welfare hub [Winter Welfare Hub - Pan Thames Paediatric Long Term Ventilation Network](#)

Damp and Mould advice for patient and families [Damp & Mould Advice for patients - Pan Thames Paediatric Long Term Ventilation Network](#)

Damp and mould tool kit for health professionals [Copy of DAMP AND MOULD CHECKLIST](#)

Appendices

A. Glossary of terms

BCYP Babies, Children and Young People

HAP Hospital Admission Protocol

LTV Long-Term Ventilation

NCPOD National Confidential Enquiry into Patient Outcome and Death

NIV Non-Invasive Ventilation

NTPN North Thames Paediatric Network

RAP Respiratory Action Plan

STPN South Thames Paediatric Network

Tr LTV Tracheostomy Long-Term Ventilation

B. Useful contacts

Pan Thames LTV Programme Team Email: gstt.panthamesltv@nhs.net

Pan Thames LTV Programme Education Team Email:
gstt.panthamesltveducation@nhs.net

NTPN website [Home - North Thames Paediatric Network](#)

STPN website [STPN homepage | South Thames Paediatric Network](#)

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