



PPLLTV

Paediatric Pan London Long Term Ventilation

PPLLTV / NTPN/STPN

Guidance for completing Paediatric Respiratory Action Plans (Tracheostomy LTV & NIV/CPAP)

The purpose of these templates are to provide a consistent format for clinicians to adapt as required when providing individualised guidance for families and carers around managing respiratory deterioration in the community setting. This document is usually provided alongside further supporting information around the child's condition and respiratory management.

There is a template for children requiring ventilation via tracheostomy, and an alternative for those using NIV/CPAP.

The plan is split into left hand columns that describe what might be observed, whilst the actions to be undertaken are outlined on right hand side.

1. The green section should describe what is usually observed on a "well" day for this child, and what interventions/ support are provided
2. The orange section should describe what may be seen with respiratory deteriorations, and the recommended actions to be taken by family/carers (under most circumstances this includes taking the child for medical review)
3. The red section should describe what may be seen in an emergency along with actions to be taken

NB for more complex patients teams can consider an additional yellow section (before the orange) giving advice regarding steps to escalate management at home in liaison with the respiratory team but without the need for face to face hospital review.

The following example provides details of information that it may be useful to include within the plan (just for guidance. Teams should use these templates as they feel appropriate)

1. For Tr-LTV
2. For NIV/CPAP users

Word templates are available alongside this guide to allow clinical teams to add individualised guidance, teams may wish to add trust logos to the templates before finalising, along with key contact details. Basic pdf templates are also available via <https://www.wellchild.org.uk/for-professionals/research-resources/10-principles-for-complex-discharge/>

Plans should be signed off in accordance with local practice (and word documents ideally shared as pdf to minimise accidental changes)

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Additional logos to be agreed and added
Respiratory Action Plan (Tracheostomy-LTV)

Name: DRAFT NHS no:

Respiratory Status (what carers may observe)		Action (what carers should do depending on level of urgency)	
Appearance/ Behaviour	<i>Description of normal interactions/ behaviour, Description of normal HR etc.</i>	Activity	<i>Description of normal daily activities</i>
Airway/ Ventilation	<i>Description of normal breathing pattern, SpO2, RR etc</i>	Airway / Ventilation	<i>Tracheostomy type (and cuff management if applicable) Description of usual ventilator dependence when well (including settings, dry circuit use etc)</i>
Secretions	<i>Description of normal secretion volume and type</i>	Airway Clearance	<i>Summary of any usual airway clearance/ frequency of suction required etc.</i>
Cough	<i>Description of usual cough strength, any other notes</i>		
Appearance/ Behaviour	<i>Description of changes in appearance/ observations that should indicate the need for hospital review</i>	Activity	<i>Description of modifications to usual activity required eg additional rest periods as required, school to notify parents to collect, limit exercise/rehab etc</i>
Airway and Ventilation	<i>Description of changes to breathing pattern, SpO2, RR that may indicate need for review</i>	Airway / Ventilation	<i>Description of any actions to be taken re: Tracheostomy/ ventilation/ humidification etc eg secondary settings, using ventilator +/- humidification for longer periods etc</i>
Secretions	<i>Description of changes that might be observed</i>	Airway Clearance	<i>Description of any changes to be made to airway clearance</i>
Cough	<i>Description of changes observed</i>		
Action: contact	This will usually be to arrange review at local hospital (A&E or direct access) Local team to contact [specialist centre] for further advice		
Appearance/ Behaviour	<i>Description of changes in appearance/ observations that indicate a respiratory emergency</i>	Activity	<i>Description of modifications to be made eg minimise activity</i>
Airway/ Ventilation	<i>Description of changes seen that indicate a respiratory emergency</i>	Airway / Ventilation	<i>Description of any actions to be taken re: tracheostomy/ ventilation whilst awaiting ambulance eg secondary settings, entraining O2 etc</i>
Secretions		Airway Clearance	<i>Description or refer to any emergency airway clearance plan (whilst awaiting ambulance)</i>
Cough			
Action:	<i>Dial 999 for ambulance. They will take to local A&E (or as arranged) Basic life support if necessary Local hospital to contact specialist centre to discuss</i>		

Plan completed by:

Date:

Reviewed by Respiratory Consultant:

Date:

Respiratory Action Plan (Tracheostomy-LTV)

Name: NHS No:

Hospital Emergency Plan

In addition to the guidance provided within the home action plan overleaf:

1. Review previous microbiology results when starting antibiotics.
 2. Perform blood gas, electrolytes, viral PCR screen, chest x-ray
 3. Settings may be changed in hospital if more support required (To discuss with respiratory centre)
 4. Have a low threshold for referring / admitting to hospital. Especially if multiple presentations for same episode of illness, not improving with oral antibiotics started previously, abnormal results or parental concerns.
 5. Please discuss all ED attendances with paediatric respiratory team via Respiratory Registrar (contact see above) and/or additional contacts noted
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Additional team contact details.....

Respiratory Action Plan (NIV/CPAP)

Name: **NHS No:**

Respiratory Status (what carers may observe)		Action (what carers should do depending on level of urgency)	
Appearance/behaviour	<i>Examples of usual activity, interaction and behaviour during the day. Normal HR, RR, SpO2</i>	Activity	<i>What activity the child usually undertakes when "well" eg attends school, plays sport, uses standing frame etc.</i>
Breathing	<i>Normal effort of breathing</i>	Ventilation	<i>Description of usual ventilator dependence and key settings</i>
Secretions	<i>Description of secretion volume and type on a normal "well" day</i>	Airway Clearance	<i>Description of normal airway clearance routine (or refer to more detailed document)</i>
Cough	<i>Description of cough type, frequency, strength</i>		
Other	<i>Particularly for NMD's is may be useful to include description of usual vocalisation and swallow</i>	Feed	<i>Description of usual feeding regime</i>
Appearance/behaviour	<i>Eg Less energy, feels tired</i>	Activity	<i>Description of what adaptations are recommended to usual activities eg. School to contact family for collection, not to do hydrotherapy/ standing frame etc</i>
Breathing	<i>Description of how breathing changes</i>	Ventilation	<i>What to do in terms of ventilation/ humidification eg use ventilator for rests during day as required, switch to unwell/secondary settings, use humidified circuit</i>
Secretions	<i>Describe change in colour/thickness/volume of sec's etc</i>	Airway Clearance	<i>Description of recommended changes to airway clearance routine (or refer to more detailed document)</i>
Cough	<i>Description of change in cough that may be seen</i>		
Other	<i>Particularly for NMD's it may be useful to explain that reduced swallow/ vocalisation can indicate respiratory compromise</i>	Feed	<i>Any recommendations re: holding feeds, optimising hydration etc</i>
Action: Contact	This will usually be to arrange review at local hospital (A&E or direct access) Local team to contact [specialist centre] for further advice		
Appearance/behaviour	<i>Signs observed that indicate a severe deterioration</i>	Activity	<i>Eg minimise activity</i>
Breathing	<i>Description of what might be seen that indicates a severe deterioration</i>	Ventilation	<i>What to do in terms of ventilation whilst awaiting ambulance eg entrain O2, secondary settings, use ventilator during transport etc</i>
Secretions	<i>Changes that might be observed</i>	Airway Clearance	<i>Any emergency airway clearance recommendations</i>
cough	<i>Eg Weak/absent on command/spontaneous</i>		
Other:	<i>Eg Weak, inaudible, gasping</i>	Feed	<i>Eg Consider holding feeds</i>
Action:	<i>Eg Dial 999 Basic life support if required (take NIV off) Ambulance takes to nearest hospital A&E liaise with specialist respiratory centre</i>		

Respiratory Action Plan (NIV/CPAP)

Name: NHS No:

Hospital Emergency Plan

In addition to the guidance provided within the home action plan overleaf:

1. Review previous microbiology results when starting antibiotics.
 2. Perform blood gas, electrolytes, viral PCR screen, chest x-ray
 3. Settings may be changed in hospital if more support required (To discuss with respiratory centre)
 4. Have a low threshold for referring / admitting to hospital. Especially if multiple presentations for same episode of illness, not improving with oral antibiotics started previously, abnormal results or parental concerns.
 5. Please discuss all ED attendances with paediatric respiratory team via Respiratory Registrar (contact see above) and/or additional contacts noted
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Additional team contact details.....