

## Quick reference guide for children on long term ventilation (LTV) admitted to a DGH during covid-19 emergency period

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This guide is for any staff member in a District General Hospital that is involved in the clinical management of patients requiring ventilation either by mask or tracheostomy.

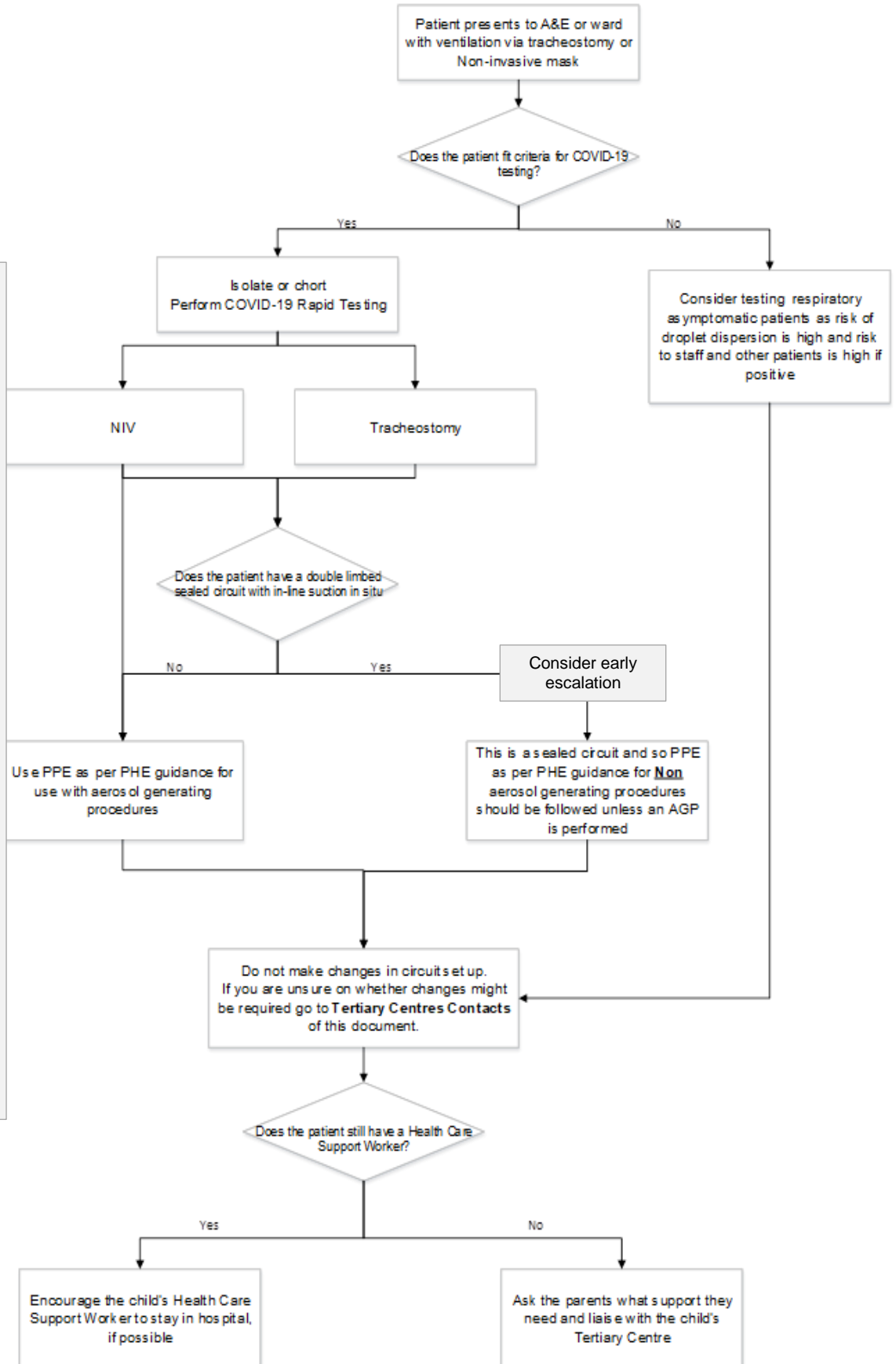
If a child or young person on established LTV presents acutely unwell follow the patient’s standard escalation procedure including calling STRS / CATs as necessary.

## 1. Pathway for a child on established LTV displaying or not covid-19 symptoms

### Aerosol generating procedures in relation to LTV are as follows:

- Open suction
- Tracheostomy removal or insertion
- Single limb ventilation via tracheostomy or NIV with unfiltered exhalation port (this is the majority of LTV children in the community).
- Tape changes
- Inner tube changes
- Cuff deflation/inflation
- Filter changes
- Circuit changes

For advice in reducing aerosol generation for these patients please contact the child's respiratory centre.



## 2. How to seek advice and support

- For **clinical support** contact the Tertiary managing centres as a first line. As the situation remains fluid, we will aim to review this section regularly. As of 31.03.2020 the advice from centres below is for:

|                                 |  |
|---------------------------------|--|
| <b>Evelina London patients:</b> | Please follow advice on the child's emergency respiratory care plan. If child is unwell with respiratory compromise, please bleep the Evelina Respiratory fellow via switchboard (020 7188 7188) on bleep 1468 during working hours or the paediatric team on bleep 0317 out of hours. Alternatively, you can speak with the HDU team on 02071886087.  |
| <b>King's College patients:</b> | Please follow advice on the child's emergency respiratory care plan. Contact the respiratory registrar on bleep 397 via switchboard 020 3299 9000 or CNS in office hours 020 3299 4580/7048, out of hours to contact the respiratory consultant on call or Thomas Cook HDU on 020 3299 5660 or PICU on 020 3299 2313.  |
| <b>St George's patients:</b>    | Please follow advice on the child's emergency respiratory care plan. Contact LTV and Respiratory CNS on 02087254216. For urgent advice overnight contact PICU. Hospitals switch number 0208 672 1255   |
| <b>Brompton patients:</b>       | Please follow advice on the child's emergency respiratory care plan. Continue to contact the LTV team during normal working hours (mon-Friday 8-4) on 07580887048 or 07791087010 and or the on-call Paediatric Respiratory SpR via switchboard 0330 128 8121 out of hours if you require clinical or technical advice.   |
| <b>GOSH patients:</b>           | Please follow advice on the child's emergency respiratory care plan. Contact the respiratory registrar via switchboard 020 7405 9200 or contact the NIV and TrLTV CNS for NIV 02074059200 Ext 1726/8761 or email <a href="mailto:Victoria.robinson@gosh.nhs.uk">Victoria.robinson@gosh.nhs.uk</a> / <a href="mailto:garry.rendle@gosh.nhs.uk">garry.rendle@gosh.nhs.uk</a> We may be deployed to other clinical areas at any time point and the NIV service may have limited cover. For LTV 02074059200 Ext 5519 or email <a href="mailto:jenny.taylor@gosh.nhs.uk">jenny.taylor@gosh.nhs.uk</a> . |
| <b>Royal London patients:</b>   | Please follow advice on the child's emergency respiratory care plan. Contact the LTV team (0203 5940489, :07715 038 332) or respiratory sleep physiologist (07701004462) during normal working hours or the on-call Paediatric Respiratory Consultant via switchboard out of hours if you require clinical or technical advice.  |

- If it is an **equipment issue** and the local team is unavailable, then the LTV team may be able to support during daytime hours [childrensltv@rbht.nhs.uk](mailto:childrensltv@rbht.nhs.uk)
- If it is a **discharge issue or issues with allowing the child's Health Care Support Worker to stay in hospital**, do contact the child's CCG as per advice in Appendix B and A, respectively. Should you have difficulties contacting the child's CCG, please contact [england.stpn@nhs.net](mailto:england.stpn@nhs.net) if you are in the South Thames Paediatric Network and [england.ntpn@nhs.net](mailto:england.ntpn@nhs.net) if you are in the North Thames Paediatric Network and we will try to escalate your request.

### **3. Quick advice and training on the use of ventilators and consumables**

If you are unsure on how to use the child's ventilator and/or have questions with regard to consumables, visit the Children's LTV service webpage on <https://ltv.services/>  
Please share this link with colleagues.

If you are worried about shortage of consumables, do consider couriers to get these delivered to you from the child's Tertiary Centre.

### **4. Advice for families**

In light of escalating concerns from families with children on LTV about COVID-19 colleagues from specialist paediatric hospitals across the South Thames and the North Thames Paediatric Networks in partnership with Well Child and the Children's LTV service shared some advice for parents and guardians of children who require home ventilation. Here is the link [www.wellchild.org.uk/covid19ltvadvice](http://www.wellchild.org.uk/covid19ltvadvice)  
The webpage will be made accessible in the next few days. Please circulate this link with your colleagues, patients and families.

## Appendix A – Agreement to allow Health Care Support Workers to stay in hospital

We have made contacts with our STP and CCG colleagues across the region and requested to temporarily support the model to allow a child's Health Care Support Worker to stay with the child in hospital during admission even if a contract between the family, the CCG and the care provider is not in place yet when:

- The child's local hospital is short staffed as staff is being re-deployed to adult services and/or
- The child requires hospital stay for clinical reasons and the child's family needs some support in hospital in the form of respite care.

This is to support hospitals and families during COVID-19 emergency period and funding might be sought through the funding made available by the Government to respond to COVID-19 emergency period

<https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/covid-19-discharge-guidance-hmg-format-v4-18.pdf>

If a child or young person on LTV is admitted to hospital, consider whether this model would be helpful to support hospital staff and/or the family.

We thank colleagues from the East London Foundation NHS Trust's Newham team that have shared with us their model of good practice. The governance around this model is outlined in the paragraphs that follow.

This is an agreement between the child's parents, the child's CCG, the child's Community Children's Nursing Service, and [insert care provider details] to cover the procedures in place for when [child's name]'s care package staff are present with him/her in hospital.

- Child's Name:
- Parents details:  
Mother:  
Father:
- Named contact at [Insert CCG Details]:
- Named contact at [Insert Care Provider Details]:
- Continuing Care Nurse Specialist [Insert Details]:

This agreement has been put in place to safeguard the child and the agency nursing/health care support worker staff that care for them during emergency or planned hospital admissions. The child's joint health and social care package is in place to support the family in caring for the child and is not to take over his/her care in its entirety.

This document is an agreement for which when the child is admitted as an inpatient in hospital the health funded [nursing support/health care support worker] care package can continue. Any important clinical decisions not covered by routine procedures or interventions will be made by parents once liaison with the appropriate nursing and medical staff has taken place.

### Process and communication

1. Hospital staff inform parents about possibility to allow the child's Health Care Support Worker to stay in hospital.
2. Parents send a copy of this agreement (include the child's name, date of admission to hospital, hospital team's email address, and signature) via email to their child's continuing care nurse specialist expressing the amount of support needed and follow up with telephone call.
3. The continuing care nurse specialist emails the child's care provider, CCG and Social Care leads:
  - To inform them that the child has been admitted to hospital and to agree the amount of time the Health Care Support Worker will spend in hospital.
  - With a copy of this agreement signed by the child's parents and the continuing care nurse specialist.
4. The child's care provider, CCG and Social Care lead return a signed copy to the continuing care nurse specialist.
5. The continuing care nurse specialist sends one copy signed by all interested parties to the parents and one to the hospital team where the child is admitted.
6. The hospital team puts a copy of this agreement into the child's nursing folder and medical notes.

**This agreement must be signed by all parties before the Health Care Support Worker is allowed to stay in hospital.**

As soon as a date for discharge is confirmed, parents must inform the child's continuing care nurse so that all relevant parties can be made aware. In their absence, **[Insert here]** should be contacted via the **[insert here]**.

### Hospital Role

- The hospital trust where the child is admitted is responsible and accountable for the child's medical needs during their admission.
- They must communicate any issues or concerns with parents, not only with the agency nursing staff caring for him/her.
- The ward must ensure that the child is adequately cared for with help from their care package staff, not solely by the care package staff.
- The medical teams should anticipate when the child is likely to be discharged and communicate this with parents in a timely manner to ensure the child is discharged safely.
- The allocated ward nurse for must communicate with the care package staff member regarding tasks to be carried out by each party to ensure that your child's needs are all met.

- The allocated ward nurse must liaise with the family to obtain rotas and gain updates of expected Health Care Support Worker and/or other family members.
- The ward staff should cover a suitable agreed rest break for the care package staff member present per shift.

### Parent's Role

- Parents will be expected to stay with the child until they are fully admitted to the ward, this is to ensure that the ward nursing team can carry out any admission paperwork and that the paediatric medical team review your child with you present (if required).
- With reduced carers available, the family must consider when the child's needs are greatest for example daytime vs night time and when it is preferable for them to get support. The family must have a discussion with the care provider and priorities staff to the busiest or most care-demanding part of the child's day.
- Parents must be present on the ward with their child at least once per day to receive updates from the medical team and provide and discuss consent for any change in treatment or procedures required. If they are unable to attend due to extenuating circumstances they must call the ward to make contact and obtain an update on their child's current condition.
- Parents are responsible for providing the ward with an adequate supply of nappies, clothes and regular medications for their child.
- Parents are responsible for communicating their child's admission details to their continuing care nurse and any other relevant parties. Parents and the care provider must ensure that package staff members who attend the hospital shifts with the child are aware of this agreement and their role.

### Role of Community Children's Nursing Service (CCNT, Diana and Continuing Care)

- The child's named community nurse should be informed of the child's admission by the continuing care nurse.
- They may visit the child in hospital to support with their care planning if needed.
- Once the child's community nurse is informed that the child will be discharged they should follow guidance provided by local CCG as per the Government's requirements <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/covid-19-discharge-guidance-hmg-format-v4-18.pdf>

### Care Package Staff Member's Role

- The child's Health Care Support Worker who works in the hospital setting must submit his/her signed timesheets to his/her care provider in a timely manner so that these can be cross checked against the time spent in

hospital. The child's care package shift times will remain the same as when they is at home unless the care provider is given notice of request of a change in shift time.

- The child's Health Care Support Worker will attend to needs that are usually met at home; other needs will require ward staff intervention.
- If there are any issues with the tasks identified below then parents must be contacted, parents should then contact the relevant parties if needed.

**Tasks** that **CAN** be carried out by the child's care package staff whilst admitted in hospital include:

- Attending to the child's personal care needs – washing, dressing and continence care.
- Airway management to the point of their usual level of naso-pharyngeal and oro-pharyngeal suctioning.
- Daily physiotherapy as usually carried out at home – as tolerated.
- Enteral feeding as per the child's usual care plan – any changes to this must be confirmed with parents prior to staff changing the feed/feed plan.
- Gastrostomy care – cleaning, reporting concerns, aspirating.
- Report concerns if the child deteriorates beyond their current clinical state.
- Report improvements from the child's initial presentation.
- Administration of medication included on your child's current community medication administration record.
- Manual handling tasks deemed suitable for one person.

**Tasks** which **SHALL NOT** be carried out by the child's care package staff are as follows:

- Consent for any interventions by the nursing, therapy or medical teams.
- Clinical Observations and Paediatric Early Warning Scoring (PEWS).
- Intravenous antibiotics, intravenous cannula care and observation for phlebitis.
- Respiratory physiotherapy that would usually be carried out by a paediatric respiratory physiotherapist.
- Administration of medication which is not included on your child's current community medication administration record.
- Airway management above your child's usual requirements e.g. use of airway adjuncts.
- High dependency/intensive care such as observation whilst on Optiflow, CPAP, BiPAP or invasive ventilation. – The carer would not be in place on ITU

The care package staff must maintain their usual responsibilities as below:

- Support family members in meeting their child's medical needs as they would at home



- Observe and monitor the child's wellbeing and report any changes to family and staff
- Ensure that appropriate privacy is given to the family and maintain confidentiality at all times unless this poses a risk to the child's safety
- Provide care as stated in care plans
- Document medication administration on the medication administration record provided, as agreed with ward staff
- Adhere to all guidelines regarding checking of equipment and emergency supplies.
- Adhere to Trust policies and procedures, in particular no smoking and no alcohol within the home/hospital or when on duty, and also to not be under the influence of alcohol or other substances when reporting for work.
- Remain awake during night shifts
- Wear appropriate clothing as per the trust policy. Appropriate footwear (i.e. flat closed shoes) must be worn at all times when giving care.
- Ensure they wear their ID badges at all times and introduce themselves to other professionals
- Staff will not answer the family's telephones unless in an emergency
- Staff will leave the child's room/bed space as found at beginning of their shift
- Staff to provide their own food and refreshments (tea/coffee/milk)
- Staff are not to use personal phones during the hours of work unless in an emergency.

Their role **DOS NOT** include:

- Domestic tasks not directly related to the child's health needs or equipment.
- Child care of siblings.
- Transport of the child or any family member in their own vehicle

I have read and understood the information outlined in this document.

| Name | Role  | Signature | Date |
|------|---|-----------|------|
|      | Father  |           |      |
|      | Mother  |           |      |
|      | Head of Commissioning & Transformation – Maternity & Children |           |      |
|      | Care Provider   |           |      |
|      | Continuing Care Nurse Specialist                              |           |      |

May include – ward manager, CNS, social worker

## Appendix B – Discharge during COVID-19 emergency period

Refer to the Government's guidance around discharge

<https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/covid-19-discharge-guidance-hmg-format-v4-18.pdf>)

Please liaise with your CCGs with regard to updating your processes and ways of working to deliver the discharge-to-assess model.

All patients who are not required to be in hospital and are therefore suitable for discharge will be added to the discharge list and allocated to a discharge pathway.

On decision of discharge, the patient and their family or carer, and any formal supported housing workers should be informed and receive the relevant leaflet (see Annex D of the Government's COVID-19 Hospital Discharge Service Requirements).

The South and North Thames Paediatric Networks have written a letter to colleagues in STPs and CCGs to call to support mitigating the risks for children and young people on LTV and their families during COVID-19 and we are liaising with hospices and rehabilitation centres to streamline access for these families.

We are keen to provide support to colleagues during these very difficult periods and to ensure that communications are cohesive and we hope this information is helpful. Please get in touch should you require any further information at [england.stpn@nhs.net](mailto:england.stpn@nhs.net) and [england.ntpn@nhs.net](mailto:england.ntpn@nhs.net) for the South and North Thames Paediatric Network, respectively.