

1<sup>st</sup> April 2020

**To Children and Young People Leads  
across STPs and CCGs  
in London, Surrey, Sussex and Kent**

Dear Colleague,

Current evidence is that COVID-19 is generally much milder in children. However, it is important that our efforts to support adult services do not impact care as usual for the most vulnerable children and young people (CYP).

**Children on Long Term Ventilation (LTV)** are part of a group of 10% of children with medical complexity that uses 50% (£115m) of specialised resources in Paediatric Intensive Care Units. The South and North Thames Paediatric Networks have approximately 1,040 CYP on LTV.

Often CYP experience delays in their discharge from hospital to home. The main reasons for these delays are 1) decisions on care package from funding panels, 2) having a suitable home property, and 3) availability of trained care provider staff. Based on findings from the NCEPOD review, delay at discharge due to non-clinical issues accounted for 41.3% of these delays (NCEPOD, 2020).

Furthermore, readmissions to hospital are frequent for these CYP. 72% of calls from CYP on LTV received by the South Thames Retrieval Service in 2018 were retrieved. Based on findings from the NCEPOD review, 46.9% CYP on LTV had an acute admission to hospital in the previous six months. 82.4% admissions were unplanned, 35.3% CYP had more than two admissions, and two had more than ten (NCEPOD, 2020).

Meeting the **Government's objective of not keeping patients in an NHS bed unless required to be in hospital during the COVID-19 emergency period** (paragraph 1.2 of the *COVID-19 Hospital Discharge Service Requirements* document - see Reference section at the end of this document) will be extremely challenging for CYP on LTV. During this time it is particularly important that we mitigate risks for these CYP to stay longer and/or be admitted inappropriately to hospital. With this in mind, the South and North Thames Paediatric Networks have identified **five likely risks**:

1. Increased delays in discharge due to either lack of Health Care Support Workers available for training or to lack of suitable housing.
2. Breakdown of care packages as a result of either Health Care Support Workers self-isolating, becoming sick themselves or the child's family displaying symptoms making it unsafe for the Health Care Support Worker to attend the home. The likelihood of the latter happening is augmented by the scarce PPE available in the community.
3. Lack of a 'place of safety' for these CYP should the care package break down and the family are unable to cope at home as a consequence.
4. Lack of accessibility of PPE for care providers and families on PHBs.

5. Hospitals are short staffed as more paediatric staff are being re-deployed to adult services.

**With support from the funding made available by the Government** to fund the cost of new or extended out-of-hospital health and social care support packages during the COVID-19 emergency period (point 10 of the *COVID-19 Hospital Discharge Service Requirements* document), the **South and North Thames Paediatric Networks call colleagues across STPs and CCGs in London, Surrey, Sussex and Kent to mitigate the risks** listed above by:

1. Working collaboratively with colleagues in acute Trusts to **prioritise discharge for CYP on LTV**. Most of these CYP will fall into pathway 1 of the discharge-to-assess model. Providers of community health services will need to lead on this pathway as explained at point 1.10 of the *COVID-19 Hospital Discharge Service Requirements* document (see Reference section at the end of this document).
  - ✓ Ensure all acute Trusts in your region are informed about new processes around discharge and have contacts of their discharge leads in the community.
  - ✓ If a child is **waiting for a suitable home**, consider temporary discharge to local hospice or rehabilitation centre.
    - The South and North Thames Paediatric Networks are currently liaising with hospices and rehabilitation centres across the region and working towards streamlining access for these children (Appendix A of this document).
    - CCGs are expected to co-ordinate and lead the rapid implementation of the Capacity Tracker and NHS mail in hospices and rehabilitation centres throughout their local area by 1<sup>st</sup> April 2020 (see Annex F of the *COVID-19 Hospital Discharge Service Requirements* document). The tracker will need to be made available to providers of community health services leading on the new discharge process.
  - ✓ If a child is **waiting for a trained carer**, please ask the family whether they have a family member that can offer temporary support.
    - If so, liaise with the Children's LTV service commissioned by NHS England and Improvement at [childrensltv@rbht.nhs.uk](mailto:childrensltv@rbht.nhs.uk).
    - Alternatively, approach care providers that offer emergency support (e.g. MedGen).
2. Ensuring **community services** have enough capacity to **monitor and risk assess care packages / personal health budget on a weekly basis** for families with a child or young person on LTV.

Further support should be provided to those families for which extra support is required to maintain the child's safety in the home environment. Such support might be offering some hours of respite care or training a family member. If the latter is a solution the family is happy with, liaise with the Children's LTV service at [childrensltv@rbht.nhs.uk](mailto:childrensltv@rbht.nhs.uk). Alternatively, approach care providers that offer emergency support (e.g. MedGen).

- 3. Using the funding** made available by the Government to manage the COVID-19 emergency period **to support hospices, rehabilitation centres and special needs schools** financially so that they can **be a temporary 'place of safety'** for these children should the child's care package break down and the family are not able to cope at home. This should help prevent unnecessary admissions to hospital for CYP on LTV who are otherwise well.

Annex B of the *COVID-19 Hospital Discharge Service Requirements* document lists the criteria for a patient to be in hospital during COVID-19 emergency period.

- 4. Ensure Hospices, Rehabilitation centres, Care Providers and all families** who have access to continuing care in your borough **are well informed about the criteria and the process for accessing COVID-19 Rapid testing and PPE in the community, including FFP3 masks and disposable gowns.** This is particularly important for Hospices, Rehabilitation centres, Care Providers and families on PHBs.

Further guidance on PHBs can be found here

<https://future.nhs.uk/connect.ti/PCCN/groupHome>

Hospices, Rehabilitation centres and Care Providers will not be able to provide support unless adequate testing and PPE is made available to them by the NHS.

- 5. Should the child need admission to hospital for clinical reasons** and the **child's Health Care Support Worker be able to support the family during the child's hospital stay**, liaise promptly with the child's Care Provider to arrange this based on the principles listed in Appendix B.

Ensure you communicate to the acute Trusts in your patch that you endorse this model should they be short staffed and the family needing extra support.

On a final note, in partnership with Well Child we have created an informational video for families with a CYP on LTV. 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 share it with colleagues and families.

If there are queries which you would like to raise, which are not already covered in existing processes or guidance documents, please contact a member of the team to raise these.

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.

Kind regards,

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South Thames Paediatric Network

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## Appendix A – suggested operational model with hospices and rehabilitation centres across the South and North Thames Paediatric Networks

The South and North Thames Paediatric Networks are currently liaising with hospices and rehabilitation centres across the region and working towards streamlining access for these children.

The questions we are asking colleagues in hospices and rehabilitation centres are the following:

- Would you require the child to be tested COVID-19 negative before acceptance into your care?
- Would you need one carer/parent to remain with the child?
- Do you need any support in staff training for ventilated children?
- Do you have transport available to collect children?

Details of the pathway, including minimum requirements for testing and PPE, will be circulated in a separate document shortly.

## Appendix B – 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 oropharyngeal 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

**Reference:**

HM Government (March 2020). *COVID-19 Hospital Discharge Service Requirements*. Available from: <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/covid-19-discharge-guidance-hmg-format-v4-18.pdf> [Accessed 23rd March 2020]

NCEPOD (February 2020). *Long Term Ventilation: Balancing the Pressures*. Available from: <https://www.ncepod.org.uk/2020ltv/LTV%20Full%20report.pdf> [Accessed 20<sup>th</sup> March 2020]