

LTV service pandemic action plan for commissioners, clinicians and care providers

Updated- 06/04/2020

Rationale:

In light of escalating concerns re COVID 19 the LTV team have generated the following advice for those children who require home ventilation for commissioners, clinical staff and external carers. A separate information letter is being provided for families.

Overall Aim:

- Minimise exposure of patients, their families and staff members to risk of COVID 19 infection
- Maintain respiratory and LTV team critical services and avoid unnecessary reviews at hospital
- Maintain patient safety when there are limited resources

Alder Hey will be reducing elective activity

- Outpatients: We are offering telephone consultations which we will use to triage need for hospital based reviews. We have therefore postponed all non-urgent consultations.
- Elective admissions: We have cancelled all planned admissions. All children will remain on their current ventilators. Planned ventilator swaps or ventilation initiation have been postponed till a later date. Urgent cases will be considered on a case by case basis.
- Sleep service: All inpatient sleep studies have been cancelled. We will continue to offer home limited channel studies measuring oxygen and carbon dioxide (Tosca studies) on an urgent basis which will be reviewed by the LTV/ respiratory teams.
- All meetings about children and young people in your care have been cancelled or converted to conference call virtual meetings.

Currently the LTV team are conducting a virtual meeting once a week on Monday at 13.30pm via Microsoft Teams to allow in house discussion of urgent cases or to allow dial in from 3rd parties to discuss cases and operational/strategic issues at home – please email respiratorypco@alderhey.nhs.uk if you wish to join or communicate with the LTV team. This email can also be used for general day to day enquiries. They will be forwarded to a member of the LTV team.

Supporting children at home

Although children are believed to be at a lower risk than older patients, we do not fully know the risk to those who require long term respiratory support or those caring for them. Following Public Health England (PHE) advice, we define any child who is invasively ventilated (via a tracheostomy) or on non-invasive ventilation (NIV) for life support (ie cannot survive without ventilation for more than 24 hours) as being in the “**extremely vulnerable group**” who need to ‘shield and protect’. However, there may also be some children who do not require this level of ventilation but who will be in the **extremely vulnerable group** based on their other medical problems. In addition there may be reasons why it may not be possible to fully “shield and protect” a child who falls into the extremely vulnerable group. This will be assessed on an individual basis. If more advice is needed, please contact our respiratory pathway coordinator on 0151 252 5777 or respiratorypco@alderhey.nhs.uk.

Any child or young person who is on either form of ventilation (tracheostomy or NIV) at home will generate aerosols therefore carers in the home setting need to follow the PHE advice on personal protective equipment (PPE) for aerosol generating procedures at all times. **Alder Hey Children’s Hospital cannot be and is not responsible for providing training or supplying PPE to the employees of individual care teams. This is responsibility falls to the care provider companies.** For parents or family members, we appreciate it is not possible to wear full PPE, but we do recommend that a child’s carers wear the appropriate level of protection when in your home.

We are asking all community teams to be aware of what consumables they have centrally and what each family has, in case a period of self-isolation is needed. This includes backup ventilators for those families who only have one and are considered life-supported. We ask that you avoid over-stocking families and consider how to best utilise resources if supplies run low. Once items are in the family’s home, they cannot be used elsewhere especially in the case of potential COVID-19 infections. Currently it is not possible to stockpile oxygen and BOC will only replace empty cylinders with full.

We appreciate that self-isolating may place additional strain on our families. We advise the following:

- Keep in close contact with your families by phone.
- Contact local social services teams to enquire about help families with increase utility bills/ extra costs etc.
- If a child is known to a local hospice, make contact with them and explore the possibility of respite care. We will highlight our most vulnerable children and families to the hospices that support our children. Unfortunately Alder Hey Hospital is unlikely to be able to offer emergency respite if your child is well.
- The LTV team has developed videos to help support the training of additional carers/ family members in how to use the A30/A40 and trilogy ventilators:
 - <https://alderhey.nhs.uk/user-guides>
- We are asking that you advise our families NOT to contact Alder Hey for advice if your child is well as we are having an increasing number of phone calls and want to prioritise our time to those who have clinical concerns.

Further advice can be found on PHE or NHS websites. If a child or young person becomes unwell, families should follow normal pathways and procedures to seek advice and attend emergency departments if necessary, despite the current outbreak.

The typical symptoms of COVID-19 which require self-isolation are:

- Temperature >37.8
- New continuous cough

Cough may not occur in some children, particularly with a neuromuscular condition, however changes in oxygen saturation and hypoxia may be a feature. Likewise changes in secretions may also occur. There may also be myalgia (aches and pains).

If families need advice then please ask them in hours (09:00 to 17:00) to call the Respiratory Pathway Co-Ordinator on 0151 252 5777 or email respiratorypc@alderhey.nhs.uk who will direct them to a member of the LTV team. Out of hours, calls should be made to the Alder Hey switchboard and put through to the 2nd on-call paediatric registrar.

We do not want to miss other causes of infection, particularly in those children who have central access but also do not want to have children presenting to emergency departments unnecessarily. If needed, we will advise families how to unlock the ventilators and change their prescriptions remotely. **No ventilator changes should be made in the community without speaking to a member of the LTV team unless previously established as part of a care plan.** Not all patients will need to be reviewed and may be advised to self-isolate but they should have clinically input from the LTV team.

Escalation response

If the crisis continues resulting in a large number of carers becoming unwell then a significant number of LTV packages will become unsustainable with current resources.

As a team we would recommend:

- Urgent upskilling and training of all family members/friends who are willing to provide care utilising the Alder Hey training videos (see above). We accept that this level of training may not be to our usual standard. Where carers have incomplete training ie. tracheostomy trained but not ventilator trained, utilise skill sets appropriately.
- Consideration with each family as to whether a redistribution of carer cover to more labour intensive times ie. day vs night would be possible, minimising the number of carers exposed to patients and families.
- Encourage families to protect carers and maintain the packages:
 - Parent taking the lead of all routine tracheostomy changes or tracheostomy tape change with carers leaving the room while they are performed.
 - Parents taking the lead for routine suction were possible with carers leaving the room while it is performed.
- For some families in extreme situations when packages have collapsed and parents are providing all care, to avoid exhaustion a parent can be asleep in the same room next to the child or young person overnight with the alarms on the ventilator and oxygen saturation

C Halfhide/A Selby/R Trinick/C Grime/A Darbyshire/E O'Brien/M MacDonald/A Reed/K Lund

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monitoring switched on. I would ask that they inform the care provider and the LTV team if this is taking place.

- We have risk assessed our families to prioritise those children who are at higher risk due to their clinical/family demands. Commissioners and care teams may decide to re-allocate carers to children who are at the highest risk. We are happy to contribute to decisions of this nature.

We will review this guidance regularly and update as needed- please check the Alder Hey Website for updates.

The Alder Hey Long-Term Ventilation Team