

Pandemic advice for parents & guardians of children on long-term ventilation

Updated 06/04/2020

Rationale:

In light of escalating concerns re COVID-19 the Long-Term Ventilation (LTV) team have generated the following advice for the parents and guardians of children who require home ventilation. A separate information letter is being provided for commissioners, employed carers and community teams.

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 initiations have been postponed till a later date.
- 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) to be used on an urgent basis which will be reviewed by the LTV team.
- All meetings about your children have been cancelled or converted to conference call virtual meetings.

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’.

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 your GP or 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.** We appreciate it is not possible for parents and guardians to wear full PPE, but you will be ‘shielding’ with your child or young person.

We are asking all our families to be aware of what consumables they have and to liaise with your community team to discuss your needs if your family require a period of self-isolation. Currently it is not possible to stockpile oxygen and suppliers will only replace cylinders when they are empty. We also ask that you don’t stock pile consumables in your home either. We have discussed contingency measures if supplies run low and community teams can contact us if they need to.

We appreciate that if you are self-isolating this may place additional strain on your ability to cope and support your child and family. We advise the following:

- Keep in close contact with your community team by phone.
- Contact your child’s social services team to enquire about help with increase utility bills/ extra costs etc.
- If your 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 you 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 website. You can also contact us on the email address and telephone number above if your child becomes unwell and you require further advice whether this is related to a possible COVID-19 infection or not.

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

- i. Temperature $>37.8^{\circ}$
- ii. New continuous cough

The cough may not occur in some children, particularly with a neuromuscular condition, however changes in oxygen saturation may be a feature. Likewise change in secretions may also occur. Your child may also experience myalgia (aches and pains). If your child has an indwelling intravenous access line (central line, portacath etc.), please be more vigilant of signs and symptoms. If you need advice about your unwell child between the hours of 9:00 till 17:00 then please call the respiratory pathway coordinator on 0151 252 5777 or email respiratorypc@alderhey.nhs.uk. They will direct the call to a member of the LTV team within 24 hours. Outside of these hours, please call the Alder Hey switchboard and ask to speak to the 2nd on-call medical registrar. If you are concerned enough to call an ambulance, please do so irrespective of the current outbreak. Emergency departments will take steps to isolate patients as much as possible

Supporting the care package of LTV children at home.

For LTV children who require a care package at home, if the crisis continues it may result in a large number of carers becoming unwell or needing to be isolated. This will result in gaps in your child's care package. Here are a few recommendations from the LTV team:

- Think about your consumable resources and use them for longer than our usual recommendation. For example, invasive ventilation circuits should usually be disposed of after one week's use but this may have to be extended if necessary. Discuss this with your child's community teams and carers. Non-invasive ventilation tubing should be washed and re-used as usual.
- Protect your carers. While it is the responsibility of your care provider to ensure their employees (your carers) are safe in their work environment, there are steps you can take to protect them and maintain the package. For invasively ventilated children, when they are due a routine tracheostomy change or tracheostomy tape change, where possible take the lead for this and ask your carers to wait outside the room. You should also perform the majority/ all routine suction.
- Try to reduce the number of carers in your home at any one time, limiting exposure to your child and family members.
- Urgent upskilling and training of all family members/friends who are willing to help care for your child. We have developed training videos for the ventilators and tubing circuits we use (see above). We understand and accept that this level of training will not be to our usual standard.

- With reduced carers available, consider when your child's needs are greatest for example daytime vs night time. Have a discussion with your care provider and prioritise staff to the busiest or most care-demanding part of your child's day.
- Accept that new or temporary carers may not be trained in all skills e.g. they may be trained in tracheostomy cares but not ventilation. Utilise their skills appropriately.
- For some families in extreme situations when packages have collapsed and parents are providing all care, to avoid exhaustion a parent could be asleep in the same room next to the child or young person overnight with the alarms on the ventilator and oxygen saturation monitoring switched on. We ask that you inform your care provider and the LTV team if this is taking place. We may suggest that the alarm limits on your devices are tightened to improve safety.
- **DO NOT** attempt to adjust the ventilator settings without prior permission and an agreed prescription. Any wish to increase settings in the community should be discussed with the LTV clinical team.

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

Alder Hey Long Term Ventilation Team