

Coronavirus (COVID-19) – information for children, young people and families from the Non-Invasive or Tracheostomy Ventilation team

We understand that you might be worried about coronavirus – also known as COVID-19 – particularly if your child relies on ventilation breathing support through a mask or tracheostomy. This information sheet from the Non-Invasive or Tracheostomy Ventilation team at Great Ormond Street Hospital (GOSH) sets out our advice for children, young people, parents and carers who use our services.

Please read this alongside our general FAQs for families at gosh.nhs.uk/covid-19-FAQ. You can also find the latest news, information and resources in our COVID-19 information hub at gosh.nhs.uk/coronavirus-hub.

Does COVID-19 affect children?

The evidence to date shows that although children do develop COVID-19 very few children will develop severe infection with COVID-19.

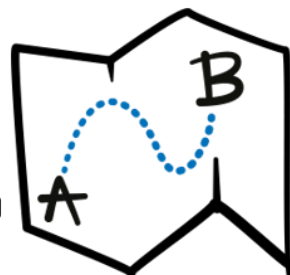
Most children infected with the virus will experience mild to moderate respiratory illness and will recover without requiring specialist treatment. However, those with underlying medical conditions such as chronic respiratory disease are more likely to develop serious symptoms.

In adults, young people and children with long term ventilator support, we would suggest the groups listed below are more vulnerable to becoming unwell with any respiratory infections including COVID-19 and should therefore be extremely vigilant in following [NHS guidance for vulnerable groups, including shielding the child](#). You may have received a letter from the

government stating that you should follow this shielding advice. We appreciate that this advice might cause anxiety, so we have put together some special guidance to clarify what this means for your child and your family, available at gosh.nhs.uk/covid-19-and-vulnerable-children.

We are recommending the following children and young people self-isolate for 12 weeks and follow advice on shielding:

- Any child who is on long term ventilation via a tracheostomy
- Any child on non-invasive ventilation who is dependent on ventilation in everyday life or when unwell
- Any child who is on long term ventilation via mask or tracheostomy due to muscle weakness
- Any child on long term ventilation via mask or tracheostomy with severe neurodisability



NHS advice states that if the rest of your household stringently follow advice on social distancing and minimise the risk of spreading the virus within the home, there is no need for them to also shield alongside the child.

If your child develops symptoms of COVID-19

- Seek clinical advice using the NHS 111 service at 111.nhs.uk or call NHS111.
- If your child has an escalation plan, please follow the plan as you would with any respiratory infection.
- If you need to escalate care, let the NIV/LTV CNS know as we may need to call ahead to your local A&E to help support remotely.
- If you have a care team, ensure you inform your care agency to make sure they have the correct personal protective equipment (PPE).
- If you are very worried about your child – they are seriously ill or their life is at risk – you should always call 999.

If you have carer support at home

There is a possibility that carers may become unwell or need isolating, which could result in gaps in your child's care. Here are a few recommendations:

- Contact your care provider and discuss alternative levels of support. For instance, consider when your child's needs are greatest, perhaps daytime vs night time, so that the care provider can prioritise staff to the time that your child requires the most care support.
- If two parents/carers are at home, you may have to do shifts to take the place of a carer if your local provider reduces the amount of support they can provide.
- In an emergency, call your local healthcare providers or your clinical team at GOSH for advice. If you are very worried about your child – they are seriously ill or injured, or their life is at risk – you should always call

999 or go to your local A&E or urgent care centre.

If a parent/carer develops symptoms, they should self-isolate and hand over care to the other parent or another family member who is not counted as vulnerable.

Specific advice about equipment and supplies from the Non-Invasive or Tracheostomy Ventilation team

If the ventilator develops problems or breaks down, follow the same guidance as usual. If you have a service contract in place, then please call the maintenance company. We have not been informed of any changes to the service during this time. If you do not have a service contract, please contact your NIV team at GOSH.

As always, make sure you have enough equipment and try to order further supplies in good time.

Non-invasive ventilation

Check you have a spare mask, tubing, filters and oxygen port (if needed). Speak to your NIV team if you need anything else.

Tracheostomy ventilation

As of May 11th 2020, we recommend that any children being ventilated at home via a tracheostomy should have their ventilator circuits changed every two weeks, rather than every week.

This is to avoid issues with ventilator tubing supply during the COVID-19 pandemic and was agreed after consideration by the Paediatric Pan London LTV Group (PPLLTV) and GOSH Respiratory Consultants. We have carefully considered the potential impact of this change and feel it is the safest approach for patients who are being ventilated at home.

While we need to change ventilator circuits slightly less frequently, please be more vigilant for signs



of infection and contact the GOSH LTV team if you have any questions or concerns.

As ever, if you are very worried about your child or their life is at risk, you should call 999 or go to your local A&E or urgent care centre.

Oxygen

We are not anticipating a shortage in home oxygen supplies, so please do not attempt to stockpile oxygen. Suppliers will only replace empty cylinders with full ones.

Specific advice about medicines from the Non-Invasive or Tracheostomy Ventilation team

Your child should continue to follow their care plan, including medication, physiotherapy and ventilation. Do not make any changes before discussing this with your specialty team.

Should we make alternative clinic appointments?

Clinicians are looking to remove the need for patients to attend face-to-face appointments wherever possible. This might involve to telephone appointments or exploring video consultations.

If your child has an upcoming clinic appointment, we will be in touch with you to discuss how we can best carry this out remotely.

All planned sleep studies have been cancelled. However if your child is due to start non-invasive ventilation, we may be able to proceed with these in exceptional circumstances. We are reviewing each case individually and will contact you to keep you updated.

Further information and support

Information from the NHS at www.nhs.uk/conditions/coronavirus-covid-19/

Information for children is available on the BBC Newsround website at www.bbc.co.uk/newsround

