

This information sheet was last updated on 3rd April 2020 at 11am

Coronavirus (COVID-19) – information for children, young people and families from the Cystic Fibrosis team

We understand that you might be worried about coronavirus – also known as COVID-19 – particularly if your child has a long-term health condition, such as cystic fibrosis. This information sheet from the Cystic Fibrosis team at Great Ormond Street Hospital (GOSH) sets out our advice for children and young people who use our services. Please read this alongside our general information about coronavirus (COVID-19) available online at www.gosh.nhs.uk/news/coronavirus-covid-19-information-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.

The Cystic Fibrosis Trust has enquired internationally for evidence of how infection with COVID-19 has affected individuals with cystic fibrosis. In those who are well it may be a mild illness, but those with significant chest problems may be at risk of more severe illness.

Your child is classed as 'vulnerable' due to their cystic fibrosis so you should follow the guidance on shielding from GOSH that is on our website.

Specific information about keeping active from the Cystic Fibrosis team

As your child will be following guidance from GOSH on shielding, they will not be able to go for a walk or cycle as they would usually. However, they should continue to do their HIIT exercise and do their physio. If you have a garden, they can

exercise there but there are plenty of options for exercising indoors too.

Specific advice about medicines from the Cystic Fibrosis team

Your child must not stop taking their medicines without first discussing with their clinical team.

If your child is taking Orkambi or Symkevi, they will need to carry on having their regular blood monitoring tests. Where possible, we will arrange for your Community team to do these, but if this is not possible, we may ask you to come to GOSH. We will confirm this with you. Remember, for your child to continue taking these medicines, it's essential we carry out regular blood tests to monitor their liver function.

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



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telephone appointments or exploring video consultations.

If your child has a clinic appointment booked this will not be cancelled. A Consultant/Fellow will call

you on your appointment day between 1.30pm and 5pm to discuss your child and make a plan.

If your appointment is to discuss the results from an Annual Assessment, this will also be done over the phone.

Further information and support

Information from the Cystic Fibrosis Trust at www.cysticfibrosis.org.uk/

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

