

COVID-19

Advice for North West CHD Network

NORTH WEST, NORTH WALES AND ISLE OF MAN CONGENITAL HEART NETWORK

*Advice for patients and families affected by congenital heart disease and
children with other heart conditions*

Updated Consensus Statement 26 March 2020

We appreciate that patients and families will be very anxious at this time. We would advise that everyone regardless of their age follow the advice being provided and updated regularly by Public Health England (PHE) and available online:

<https://www.nhs.uk/conditions/coronavirus-covid-19/>

The current coronavirus pandemic (COVID-19) is expected to affect a large number of people over the coming months. There remains very little evidence relating to patients with congenital heart disease (CHD) and the risks of infection with this new virus.

So far, it appears that most children with CHD are unlikely to be at any greater risk of COVID-19 than those in the general population. Evidence from around the world suggests the disease is much milder in children and, in fact, some may show no significant symptoms at all. The risk of becoming very unwell due to COVID-19 is low for children and younger adults.

What can you do to help reduce your chance of being infected?

1. Wash your hands with warm soapy water for a minimum of 20 seconds and dry them thoroughly. Washing in this way is the most effective way of killing the virus on your hands.
2. If you are unable to use soap and water then alcohol gel is very good to use instead.



3. Take care of your skin on your hands and use a moisturiser if necessary (do not share with anyone else)
4. Cough into tissues and dispose of them into a bin straightaway
5. Avoid touching your mouth, nose and eyes when you have not been able to wash your hands

Stay at home

Everyone must now stay at home to help stop the spread of coronavirus
This includes people of all ages even if you do not have any symptoms or other health conditions

What to do if you or your child has symptoms of COVID-19?

Do not attend unannounced at any of the hospitals that provide care for patients with congenital heart disease. This virus is highly contagious and you will put others at risk if you do this

Do not turn up at a GP surgery, pharmacy or hospital

Stay at home if you have either:

- a high temperature – this means you feel hot to touch on your chest or back (you do not need to measure your temperature)
- a new, continuous cough – this means coughing a lot for more than an hour, or 3 or more coughing episodes in 24 hours (if you usually have a cough, it may be worse than usual)

Most people will have cold or flu like symptoms and will recover from this virus

Use the 111 online coronavirus service to find out what to do:

<https://111.nhs.uk/covid-19/>

Only call 111 if you cannot get help online

What do you do if you or your child become increasingly unwell with COVID-19?

- 1. Please do not go directly to your GP practice or A+E**
- 2.** If your symptoms get worse and you cannot cope at home then go to NHS 111 online and complete an online assessment
- 3.** If you do not have access to the internet, phone 111 directly
- 4.** You may be on hold for a long time. Be prepared to wait and keep your phone charged up
- 5.** If you need to call 999 please tell them that you think you have symptoms of COVID-19 so they can prepare to pick you up safely
- 6.** Please take a copy of your clinic letter with you. Explain that you, or your child has an underlying congenital heart problem and if needed they can call the “on-call” congenital heart team for advice 24/7 via the switchboards listed below:
 - a. Alder Hey Children’s Hospital: 0151 228 4811 (paediatrics)**
 - b. Manchester Children’s Hospital: 0161 276 1234 (paediatrics)**
 - c. Liverpool Heart and Chest Hospital : 0151 600 1616 (adults)**
- 7.** Our NHS is extremely skilled in looking after sick patients and it will help them to look after your or your child safely if they have this information

What do you do if you or your child need medical help for another reason?

Please do not attend unannounced at any of the hospitals that provide care for patients with congenital heart disease. Coronavirus is highly contagious and you will put others at risk if you do this

**Please do not turn up at a GP surgery, pharmacy or
hospital**

1. For health information and advice, use the NHS website or check your GP surgery website
2. For urgent medical help, use the NHS 111 online service. Only call 111 if you're unable to get help online
3. For life-threatening emergencies, call 999 for an ambulance
4. If you are sure that the symptoms are due to you or your child's congenital heart problem (they don't have a temperature or cough) make sure you are clear about this when you are triaged. Ask the A&E staff to liaise with the congenital heart team for advice who are on call 24/7. Particularly if they are considering putting you in with other people who may be 'breathless' because of COVID-19

Advice for adults and children at **Increased Risk of Severe Illness From COVID-19**

Although the evidence is very small, patients with the congenital cardiac conditions listed below are advised to be particularly stringent in following social distancing measures. New guidance has been published by the British Congenital Cardiac Society (BCCA) together with Clinical Reference Group (CRG) and NHS England:

BCCA guidance:

https://www.bcca-uk.org/pages/news_box.asp?NewsID=19495710

- **Single ventricle patients and those with a Fontan circulation**
- **Infants < 1 year old with unrepaired congenital heart disease requiring surgery or catheter intervention e.g. VSD, AVSD or tetralogy of Fallot**
- **Those with cyanosis (oxygen saturations <85%)**
- **Patients with severe heart muscle disease (cardiomyopathy) requiring medication**
- **Patients with CHD on medication to improve heart function i.e. heart failure**
- **Patients with pulmonary hypertension (high blood pressure in the lungs)**
- **Patients with CHD plus other significant co-existing conditions e.g. chronic kidney disease or chronic lung disease.**

For advice on social distancing please follow the advice below:

<https://www.gov.uk/government/publications/covid-19-guidance-on-social-distancing-and-for-vulnerable-people/guidance-on-social-distancing-for-everyone-in-the-uk-and-protecting-older-people-and-vulnerable-adults>

Patients with reduced immunity e.g. patients with Down syndrome, or chromosome 22q11 deletion (Di-George Syndrome) and those taking long-term penicillin to prevent infection because of the lack of a functioning spleen should also follow the recommended guidance around social distancing

Advice for Adults and Children at **Very High Risk of Severe Illness from COVID-19**

This guidance is for people, including children, who are at very high risk of severe illness from coronavirus (COVID-19) because of an underlying health condition, and for their family, friends and carers. It is intended for use in situations where the extremely vulnerable person is living in their own home, with or without additional support

There are extra things you should do to avoid catching it. **This is called 'shielding'**.

You Should:

1. Not leave your home
2. Avoid close contact with other people in your home as much as possible

Who is at Very High Risk of Severe Illness from COVID-19?

You may be at very high risk from COVID-19 infection if you:

- Have had any organ transplant
- Are having certain types of cancer treatment
- Have blood or bone marrow cancer, such as leukaemia
- Have a severe lung condition, such as cystic fibrosis or severe asthma
- Have a condition that makes you much more likely to get infections
- Are taking medicine that weakens your immune system
- Are pregnant with a '**significant**' heart condition (*please see below*)

Read the full advice on protecting yourself (shielding) if you're at high risk from coronavirus on GOV.UK.

<https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19>

Important Information

If you're at high risk, you will be contacted by the NHS by Sunday 29 March 2020.

Please do not contact your GP or healthcare team at this stage and wait to be contacted

What to do if you are pregnant?

Public Health England have included pregnant women with 'significant heart disease' in the group defined on medical grounds as being extremely vulnerable from COVID-19 and advised that they should also be **shielded**. The UK Maternal Cardiology Society published updated guidance on 25/03/20 to define what 'significant' heart disease is in the setting of pregnancy. This advice is based on a consensus of expert professional opinion in the absence of specific evidence.

If you are pregnant with one of the 'significant' heart conditions listed below it is advised that you should be 'shielding'

- Impaired left heart function (any cause)
- A systemic right ventricle (congenitally corrected TGA, Senning/Mustard surgery for TGA) even if well-functioning
- Hypertrophic cardiomyopathy with abnormal heart function and/or outflow tract obstruction
- Heart disease due to high blood pressure with thickening of the muscle on the left side of the heart
- Fontan circulation
- Pulmonary arterial hypertension (any cause)
- Cyanotic conditions ie saturation in air < 92%
- Moderate or severe valve stenosis (narrowed)
- Severe valve regurgitation (leaking) and moderate if symptomatic
- Symptomatic coronary artery disease

For further information and answers to questions for pregnant ladies please refer to the guidance that has been published by the Royal College of Obstetricians and Gynaecologists.

<https://www.rcog.org.uk/en/guidelines-research-services/guidelines/coronavirus-pregnancy/covid-19-virus-infection-and-pregnancy/>

Information for patients with heart rhythm problems

Those patients with Brugada Syndrome or Long QT Syndrome (Type 3) will be at increased risk from COVID-19. This is because fever can induce dangerous rhythms. There is no evidence that this is any different to the risk caused by other illnesses that result in a high temperature.

There appears to be no increased risk for all other patients with rhythm problems including:

Long QT Syndrome

CPVT

Patients with congenital heart block

Patients with a permanent pacemaker who have a normal heart

What to do if you or your child has high blood pressure in your lung arteries (PHT)?

- 1.** If you take a special medicine to help reduce the blood pressure in your lung arteries called Macitentan or Bosentan you normally need to have a monthly blood test to check that your liver function is ok
- 2.** As long as your liver function has been stable it is quite safe for you to not have your bloods checked for up to three months. This is to help you avoid catching this virus in a busy clinic
- 3.** For specific advice relating to patients with PHT and coronavirus please visit the PAH-uk website

<https://www.phauk.org/coronavirus-pulmonary-hypertension/>

What will happen to the congenital heart services during this time?

If you have a booked outpatient appointment or admission to hospital planned in the next few weeks, please check with the hospital that you are due to attend

Clinics:

Routine clinic appointments are affected by this outbreak.

All patients due to be seen in outpatient clinic in the coming weeks are being triaged and cases prioritised by a consultant who specialises in congenital heart disease. This is likely to be the consultant that knows you or your child well.

1. Most patients will be offered a telephone consultation instead. We are choosing to do this to comply with the Government advice to **'Stay at Home'**
2. For the vast majority of patients a face-to-face consultation can safely be delayed for at least 3-6 months
3. Both paediatric and adult services are continuing to provide urgent clinics each week for patients who need to be seen in person during this COVID-19 outbreak. This might mean that you need to travel to further than normal for your appointment

DO NOT come to out-patient clinic if you or your child have a new cough and/or a temperature or have been in contact with anyone with coronavirus symptoms. Please phone your patient help-line to inform them that you are unable to attend.

Surgery and Intervention:

All routine surgical and catheter intervention procedures for congenital heart disease have now been cancelled across the North West of England. Emergency operations and catheter procedures will continue to be performed as needed.

Can I visit my child or family member whilst they are in Hospital?

DO NOT visit anyone in hospital if you or anyone that you live with have a new cough and/or a high temperature or have been in contact with anyone with coronavirus symptoms

In order to protect patients, staff and the public, hospitals are introducing new visiting arrangements. Please check these before you try and visit your loved one. The following restrictions apply in the following centres:

Alder Hey Children’s Hospital: Visitors are restricted to a maximum of two close family members or carers each day

Liverpool Heart and Chest Hospital: From 25th March 2020 all visiting is suspended except for patients who are receiving end-of-life care or patients who need to be accompanied because of special needs

We understand that this information may cause you to be worried and anxious. Please call your Congenital Heart Team via the patient help line numbers below if you have any questions about how this might affect you or your child’s care.

What if you or your child develop new symptoms ?

If you are concerned that you or your child has new symptoms related to your congenital heart problem that you are worried about please contact the Congenital Heart Team on the numbers below to discuss with a Specialist Nurse. We will make sure that patients who need to be reviewed urgently – will be seen appropriately throughout the CHD Network during this pandemic

How to contact the Congenital Heart Team if you have any further questions:

Paediatrics Helplines:

Alder Hey Children’s Hospital: 0151 252 5291

Royal Manchester Children’s Hospital: 0161 701 0664

North West Adult Congenital Heart helpline:

Liverpool Heart and Chest Hospital: 0151 254 3333

Frequently asked Questions:

ACE Inhibitors or angiotensin receptor II antagonists

Many patients with CHD or chronic heart failure may be on ACE inhibitors (e.g. Ramipril, captopril, lisinopril, enalapril), angiotensin receptor II antagonists (e.g. losartan, candesartan)

The British Cardiac Society, British Society for Heart Failure and European Society of Cardiology Council on Hypertension have said that there is no clinical or scientific evidence to suggest that treatment with an ACE inhibitor should be discontinued because of COVID-19. Stopping these medications may cause worsening of your heart condition.

Aspirin

Our recommendation is that patients who are taking aspirin continue on their treatment unless advised differently by their cardiac team.

Use of paracetamol versus ibuprofen

Although there is as yet no firm evidence, patients should use paracetamol rather than ibuprofen or other non-steroidal anti-inflammatory drugs (NSAIDs) to control fever and pain.

Removal of the Thymus

The thymus gland is routinely removed during some forms of cardiac surgery where the scar is at the front of the chest. There is no evidence that this constitutes an additional risk for infection.

Other Useful links:

Coronavirus (COVID-19): UK Government Response:

<https://www.gov.uk/government/topical-events/coronavirus-covid-19-uk-government-response>

BCCA

British Congenital Cardiac Association

https://www.bcca-uk.org/pages/news_box.asp?NewsID=19495710

The Children's Heart Federation

<https://www.chfed.org.uk/>

The Somerville Foundation:

<https://thesf.org.uk/help-advice/coronavirus/>

MIND

Looking after your mental health and well-being:

<https://www.mind.org.uk/information-support/coronavirus-and-your-wellbeing/?fbclid=IwAR3hpzrVMUiwXxqvtskEtR832pYvOlruVx4wPSNcknj0s9dWewU-PxxnXUc#collapse6a046>

Self Isolation Guidance:

<https://www.nhs.uk/conditions/coronavirus-covid-19/self-isolation-advice/>

Get an isolation note:

<https://111.nhs.uk/isolation-note/>