BRITISH CONGENITAL CARDIAC ASSOCIATION

COVID-19: BCCA updated practical guidance for patients, parents, charities and support groups, 11 June 2020

Introduction

The COVID-19 pandemic has been challenging both for those who provide healthcare services and for patients and their families. Clinical staff are grateful for the patience and support demonstrated by patients and families as they continue to work to provide good clinical care in very difficult circumstances.

While we have given the best advice we are able at this time, our understanding is rapidly developing and the course of the pandemic progressing. This means that the best advice will continue to change. There are likely to be regional differences in the course of the pandemic, and speed at which services are able to return towards normal.

Risk

COVID-19 is a new disease, so while we have learned a lot in the past few months, there is still much we don't know.

The evidence to date shows that COVID-19 presents greater risks to some people than others. Risk factors include age (older people are more likely to have a poor outcome), ethnicity (BAME people are more likely to have a poor outcome) and gender (men are more likely to have a worse outcome than women). People with conditions or on treatments that suppress their immune system are also at greater risk. The risks in children appear much lower than in adults.

We do not have enough information to make a full assessment of the risks to people with congenital heart disease (CHD) because there is no published analysis of the risk of COVID-19 in CHD. The BCCA has initiated a nationwide study to provide further information.

The BCCA has already issued advice on vulnerable and extremely vulnerable groups within the CHD population.

> BCCA COVID-19 guidance for Vulnerable groups with congenital heart disease (18 March 2020) available here: https://www.bcca-uk.org/pages/news_box.asp?NewsID=19495710

Updated BCCA COVID-19 guidance for extremely vulnerable groups with congenital heart disease (27 March 2020) https://www.bcca-uk.org/pages/news_box.asp?NewsID=19495711

Patients with CHD and their families should continue to follow government advice to reduce their risk, including social distancing and hand washing, noting that there are variations in the guidance for the four countries of the United Kingdom. While some patients will be considered vulnerable or highly vulnerable, others will not be considered at increased risk, and should follow the advice given for the general population.

The BCCA is aware that differing advice has been given to patients by different CHD centres as to who may be considered 'extremely vulnerable' to COVID 19. In the absence of direct evidence of the effect of the virus in different CHD lesions, at different ages, such differences may be expected as each clinician uses their best clinical judgement to advise patients. Such judgements must balance the benefits of shielding against the restrictions on activity and household contact that flow from following the UK Government shielding guidance. Where a clinician advises a patient that they are extremely vulnerable and should follow shielding advice, there is a formal process by which such patients can be added to the list of patients shielding and able to access the support provided.

We have seen the emergence of an apparently new condition in children, called paediatric multisystem inflammatory syndrome (PIMS). While this affects the heart in some patients, there is no evidence so far that children with pre-existing heart conditions are more at risk. The Royal College of Paediatrics and Child Health has issued guidance for professionals and, with effective early treatment, the long-term risk appears low although some children may require intensive care.

Hospital care

In common with other specialties, CHD services have needed to respond to the COVID-19 pandemic. Across the country this has seen a reduction in face to face outpatient clinics, and a focus on only the most urgent operations and cardiology interventions. Hospitals are now working hard to restore services closer to normal, but it will be some time before things are completely back to normal. Some of the new ways of working have been found to be helpful, so hospitals will be looking to make them part of normal practice in future. Over the coming months, feedback from patients will be important to understand what has worked well and what hasn't.

CHD teams up and down the country worked hard to maintain helpline services throughout. Patients and families with questions can still access helplines, and response times should now be improving. Those with greater ongoing needs will have been given access to a named specialist nurse (or the team of specialist nurses). Patients and their families should contact their usual hospital centre for advice if they are worried about their condition getting worse.

We expect to see a gradual return to greater levels of surgical activity (and similarly investigations and cardiology interventions) but once again this will not be a quick return to normal. There will be regional differences in the course of the pandemic, and

the speed at which services are able to return towards normal. The need to provide a COVID secure environment, the need for additional cleaning of facilities, the need for extra time between cases and the impact of working while wearing full PPE mean that activity will continue to be at a lower level for some months yet. Clinical teams will continue to review patients on the waiting list to make sure that care continues to be provided in a timely way.

Outpatient clinics

Face to face clinics have continued in many hospitals, but with fewer appointments to ensure that patients and staff can observe good infection prevention and control measures. In some cases, outreach clinics may be slower to restart than clinics at the main hospital.

If a patient must attend a clinic they will be asked to:

- maintain good hand hygiene – hand gel will be provided at the entrance and throughout the hospital
- keep a safe distance from other patients, and from staff where possible
- follow the signs which will indicate where to wait and queue safely.

Cardiac centres aim to minimise the number of attendances which patients have to make. Telephone clinics and in some cases video clinics have increased and allowed continuing care to be provided without the need to attend the hospital. It's likely that we will see further development of remote monitoring.

All clinic lists have been reviewed by the clinical team to ensure that an appropriate level of care is offered to each patient.

People with coronavirus symptoms, as well as members of their household, should not attend a hospital appointment, but should continue to follow the advice to self-isolate. The hospital team can provide more advice.

Advice will be given to shielded patients by the hospital if they need to attend a clinic. This will cover any special steps to be taken.

Travelling to an outpatient appointment

When travelling to a hospital appointment, patients should follow the general advice on safer travel, available here: https://www.gov.uk/guidance/coronavirus-covid-19-safer-travel-guidance-for-passengers

If possible, shielded patients should use their own transport. However, if this is not possible, they should use hospital transport. If a shielded patient arrives by hospital transport, they need to inform the transport drivers that they are a shielded patient. Shielded patients should avoid using public transport.

Healthwatch has some useful general information for patients and families about help with travel which is available here: https://www.healthwatch.co.uk/advice-and-information/2019-09-26/do-you-need-help-travelling-nhs-services

Arrival at an outpatient clinic

It is important that all patients and anyone accompanying them observe careful hand hygiene when arriving at hospital, on entering and leaving any clinical area and on leaving the hospital. This should involve washing their hands with soap and warm water for a minimum of 20 seconds or using alcohol gel if washing facilities are not easily available or practical.

If a shielded patient uses their own transport, they should inform the staff on arrival to the clinical area that they are a shielded patient.

Inpatient admissions

If a patient has a planned admission, they may need to self-isolate before and after coming to the hospital, along with other members of their household. The hospital concerned will provide further advice.

Patients will be tested for COVID-19 around the time of their hospital admission, even if they do not have symptoms.

Face coverings

The UK government has issued general advice on face coverings, available here: https://www.gov.uk/government/news/public-advised-to-cover-faces-in-enclosed-spaces

The general advice is to consider wearing face coverings in enclosed public spaces where you may be more likely to come into contact with people you do not normally meet. The advice recommends that the general public do not use medical grade face masks.

From 15 June 2020, in England, passengers will be required to wear a face covering on public transport (bus, coach, train, tram, ferry and aircraft).

From 15 June 2020, all visitors to hospitals and outpatients in England must wear face coverings at all times. Members of the public are strongly urged to attend hospital wearing a face covering, but a face mask will be provided in emergencies.

Returning to school, college, university and work

The timetable for return to education and to work is expected to follow a different timetable in each of the four nations, with regional variation also possible.

Extremely Vulnerable/Shielding

Children who have been placed into the "extremely clinically vulnerable" category by their cardiac clinical team should not re-attend school at present.

Similarly, adult patients in this group should not return to work.

People who live in a household with someone who is extremely clinically vulnerable and shielding should only attend if stringent social distancing can be adhered to and the child or young person is able to understand and follow those instructions.

Vulnerable

Parents should follow medical advice for children who are considered clinically vulnerable. Returning to school should follow a risk assessment by the school based on the clinical situation as well as the school's plans to be able to maintain social distancing and other measures to reduce the potential spread of Coronavirus.

Children and young people who live with someone who is clinically vulnerable (but not extremely clinically vulnerable) as defined in the social distancing guidance and including those who are pregnant, can attend.

The Royal College of Paediatrics and Child Health guidance states that: "Clinically vulnerable children, who are under secondary or specialist care for an underlying health condition are, on the balance of probabilities, more likely to benefit from returning to school when their year group does so. These families may need a conversation with their treating teams to balance the potential risks and any familial anxiety."

If you are in doubt about the vulnerability of your child, your cardiac unit should be able to offer advice. Where possible, and if it is essential to do so, written information may also be provided.

Similarly, employers will undertake work place risk assessments for clinically vulnerable adults who cannot work from home.

Other CHD patients, not considered to be vulnerable or extremely vulnerable, should follow government advice available here:

https://www.gov.uk/government/publications/staying-alert-and-safe-social-distancing

https://www.gov.uk/guidance/working-safely-during-coronavirus-covid-19

Testing

Testing, both for active COVID-19 infection and for antibodies will be determined by the UK Government policy at the time.

At this stage the value of antibody tests is limited to answering the question of whether someone has had the virus or not and does not give any confirmation of future immunity.

Further information is available here:
https://www.gov.uk/government/publications/coronavirus-covid-19-antibody-tests/coronavirus-covid-19-antibody-tests

Vaccination

We do not yet know when, or if, a vaccine will be available.

Prioritisation of individuals to receive the vaccine will be decided by UK government policy if a vaccine becomes available.

Research

The CHD community is very keen to see the results of focussed CHD, COVID-19 research, international and UK based studies for infants, children and adults with CHD.

At present, there is no publication which has systematically studied the risks of COVID-19 in CHD patients.

In the UK, the BCCA has initiated a study of CHD centres around the UK and Ireland about the impact of COVID-19 in their patients. This study is ongoing and ethical permission is being sought to gather more detailed information, supported by communications from major CHD charities. The main focus of research is to develop a vaccine and disease modifying drugs to prevent or treat COVID-19 infection.

Dental Services

The reopening of dental services is expected to follow a different timetable in each of the four nations, with regional variation also possible. It is likely that a full range of dental care will not be available straight away.

Advice from the General Dental Council advises that care is provided based on the urgency of needs, the particular, unmet, needs of vulnerable groups and available capacity to undertake activity.

Cardiac centres are making every effort to support patients and parents during the pandemic. Each Trust will have a patient advice and liaison service who should be involved if patients have difficulties accessing dental care.

Further information is available here:
https://www.nhs.uk/using-the-nhs/nhs-services/dentists/how-to-find-an-nhs-dentist/

Endocarditis

Endocarditis remains an important risk for patients with CHD, and the advice relating to prevention of infective endocarditis has not changed during the COVID-19 pandemic. If a patient with congenital heart disease becomes unwell, with signs of infection, they should remind those from whom they are seeking advice / care that endocarditis should be considered as a potential cause for symptoms.

BCCA, 11 June 2020