



**Kawasaki
Disease
Foundation Aust.**

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April 2020 Newsletter

Dear KD Families and Friends,

Coronavirus (COVID-19) special edition

We hope that our KD community are all well and managing as best as you can under the current unusual circumstances resulting from the COVID-19 pandemic. We understand that it's an unsettling time and know firsthand the challenges for our KD community. Our children have all been sick enough and not a single one of us wants to go through another trauma!

We have had many questions about COVID-19 and what this might mean for our KD survivors. Some of the questions include: Are our KD kids at the same risk as other kids that have not had KD? Are they more at risk of getting COVID-19? Will they develop complications if they are diagnosed with COVID-19?

What we know to date, is that children diagnosed with COVID-19 generally present with mild symptoms and recover well. This knowledge may be a small relief to any worrying thoughts! Despite the shared experiences of KD, each child's situation is unique and where medical advice is needed, please speak to your GP or contact the National Coronavirus Helpline on 1800 020 080.

There are no specific Australian, nor international, guidelines around KD and COVID-19. As things are changing rapidly, we are actively keeping up to date and closely monitoring health advice. This includes from authorities in Australia, and other KD networks internationally.

Please continue to check in on Facebook for regular updates and to connect with our community. Don't hesitate to reach out at any time as supporting each other is what helps us to get through tough times!

Warm regards and much love to everyone,

The KD Committee 

Please get in touch with us if you need support during this time.

Facebook Page: <https://www.facebook.com/kawasakidiseaseau/>

Facebook group: <https://www.facebook.com/groups/kdforaustralia/>

Website: <https://kdfoundation.org.au/>

Email: email info@kdfoundation.org.au



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What is COVID-19 – World Health Organisation



The World Health Organisation states COVID-19 is the infectious disease caused by the most recently discovered coronavirus. This new virus and disease were unknown before the outbreak began in Wuhan, China, in December 2019.

What are the symptoms of COVID-19

The most common symptoms are fever, tiredness, and dry cough. Some patients may have aches and pains, nasal congestion, runny nose, sore throat or diarrhea. These symptoms are usually mild and begin gradually. Some people become infected but don't develop any symptoms and don't feel unwell. Most people (about 80%) recover from the disease without needing special treatment. Around 1 out of every 6 people who gets COVID-19 becomes seriously ill and develops difficulty breathing. Older people, and those with underlying medical problems like high blood pressure, heart problems or diabetes, are more likely to develop serious illness. People with fever, cough and difficulty breathing should seek medical attention.

Protection measures for everyone

Stay aware of the latest information on the outbreak, available on the WHO website and through your national and local public health authority. The situation is unpredictable so check regularly for the latest news.

Source: <https://www.who.int/news-room/q-a-detail/q-a-coronaviruses>

Letter from Dr Jane Burns – COVID-19

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March 13, 2020

Dear KD Families,

We have received many inquiries at the KD Research Center from concerned parents regarding the Covid-19 virus and KD. We wanted to reach out to allay any fears by providing the following information:

- 1) There is no reason to believe that children who have recovered from acute KD with or without coronary artery aneurysms are at any increased risk of contracting the Covid-19 virus. Nor is there any concern that once infected that these children would have more severe disease.
- 2) Covid-19 virus has not caused severe respiratory disease in any children, regardless of their health history or health status.
- 3) The precautions regarding social distancing are to protect the elderly population and to prevent a large surge in adults becoming infected and requiring care.
- 4) Aspirin and other medications that your child may be taking for their KD and coronary artery aneurysms are not known to be contraindicated in the setting of Covid-19 infection.

We hope that you and your families remain healthy by following public health guidelines in your communities.

Warmest regards,

Jane C. Burns, MD
Adriana H. Tremoulet, MD
And the staff at the KD Research Center

HeartKids



What is known about how COVID-19 affects children and adults?

Information from other countries suggests that children may not be as severely affected by COVID-19 as adults. In China, out of over 2000 children infected, there were 13 critical cases and 1 death. We continue to learn more as data are shared and released. However, older adults and those with cardiovascular disease may be more likely to have severe COVID-19 symptoms and become very ill when infected. This is particularly true for adults with uncontrolled heart conditions such as congestive heart failure, hypertension (high blood pressure), or coronary artery disease, and for those with chronic lung conditions which occur in CHD patients (like asthma or pulmonary hypertension).

Should I go to work if I or someone in my family has Childhood Heart Disease?

If you are concerned that you may be at high risk for severe COVID-19, it is important to speak with a supervisor and/or occupational health person about your concerns. Employers should be aware that more employees may need to stay at home to care for sick children or other sick family members than is usual in case of a community outbreak. There may be options to telecommute or to request avoiding certain duties as a health precaution.

Extract from a recent email from HeartKids:

Hi Everyone,

With borders closing, changes at hospitals, reduction of elective surgeries and social distancing, this rapidly evolving situation occurring with respect to COVID-19 (Coronavirus) is all very unsettling.

Please if you are feeling uncertain, anxious or just want to talk to someone call:

HEARTKIDS HELPLINE ON 1800 432 785.

From Shirley Mates, KD parent:

On a personal note, HeartKids is the first support group I found back in 1994/5 when Cam got KD and as a family we have been involved with them ever since. I was on their committee for many years and we still support their activities. The Kawasaki Disease Foundation is now liaising with them more closely and in the future we hope to utilise some of their resources. They have been supporting the Foundation to distribute our information packs.

Please visit the HeartKids website for more information on:

- What is COVID-19?
- What is known about how COVID-19 affects those with congenital heart disease?
- What can I do to stay healthy?
- What should I do if I feel like I have symptoms?
- All of this is stressing me out. are there any resources to help me cope?

Source: <https://www.heartkids.org.au/whats-on/news/covid19-update>

Statement from Scientific Advisory Board of Societi, the UK Foundation for Kawasaki Disease



Statement from Societi Scientific Advisory Board 19 March 2020

Children and Young adults

The Scientific Advisory Board notes that a remarkable feature of the COVID-19 reports worldwide, is that children and healthy young adults have generally had mild disease and have recovered well.

Patients with previous Kawasaki Disease

Patients with previous Kawasaki Disease have normal immune responses to all common infections, and so there is no reason to suspect that they are any more susceptible to COVID-19 infection. There is also no reason to suspect they will suffer a more severe COVID-19 infection than other children or young adults of similar age. As noted above, research suggests that children and young adults generally have mild disease.

Please visit the Societi website for more information on:

- If you/your child is being treated with immunosuppressants or steroids
- If you/your child has been treated in the last 6 months with immunosuppressants or steroids following Kawasaki Disease
- If you/your child is being treated with other medication for the treatment of Kawasaki Disease
- Patients with existing giant coronary artery aneurysms following Kawasaki Disease

Source: <https://www.societi.org.uk/kawasaki-disease-and-covid-19/>

Australian Government Department of Health



The Australian Government Department of Health provides a wealth of information pertaining to Australian information and trends in COVID-19.

To help slow the spread of COVID-19, practise good hygiene and social distancing and follow the rules for public gatherings and self-isolation.

Please visit the Department of Health website for more information on:

- Current status
- Symptoms
- Advice for people at risk of coronavirus (COVID-19)
- How to protect yourself and others from coronavirus (COVID-19)
- If you're concerned
- Government response

Source: <https://www.health.gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert>

Healthdirect Coronavirus (COVID-19) Symptom Checker



If you are concerned about possible COVID-19 symptoms, you can access the free online Coronavirus (COVID-19) symptom checker at healthdirect. Please note that this is no substitute for actual medical advice from a qualified medical practitioner.

Source: <https://www.health.gov.au/resources/apps-and-tools/healthdirect-coronavirus-covid-19-symptom-checker>

Nigel Curtis, Australian Kawasaki Disease Specialist



Some of you may have seen Professor Nigel Curtis a couple of times recently on the news and remembered him from one of our early parent information sessions at the Royal Children's Hospital, Melbourne.

Nigel is based at the RCH and also works at the Murdoch Children's Research Institute along with our medical advisor Professor David Burgner. We also share posts from their Facebook page from time to time.

Nigel initially spoke about how to talk to your children about the current virus situation and just this week has been on the news explaining how the MCRI is trialling a vaccine on Health Care workers as another major measure to protect them.

Many hospitals have introduced measures to minimise the risk of COVID-19 transmission to staff and patients, including restrictions to visitors. In many cases visitors to only one family member, or parent/guardians only and for a specified duration. This can add further emotional challenges to an already stressful time, so please reach out to us if you need someone to talk to.

The Royal Children's hospital and the Perth Children's Hospital have also released information videos:

- RCH: Keeping healthy and staying safe
- RCH: Talking to your child about COVID-19
Both at [https://www.rch.org.au/rch/Coronavirus_\(COVID-19\)/](https://www.rch.org.au/rch/Coronavirus_(COVID-19)/)
- PCH: Coronavirus, what parents needs to know
- PCH: How to talk to children about coronavirus
Both at <https://pch.health.wa.gov.au/About-us/News/Coronavirus-what-you-need-to-know>

Other useful resources:

- **Coronavirus and the CHD patient:** Adult Congenital Heart Association webinar 16 March 2020 <https://youtu.be/hou2qM1phVQ>
- **Coronavirus and children in Australia** <https://raisingchildren.net.au/guides/a-z-health-reference/coronavirus-and-children-in-australia>

Supporting your Mental Health



The experience of Kawasaki Disease is emotionally and physically taxing. Not only for the patient, but also for parents/guardians, and other family members. Other challenging factors can present at the same time as the KD experience, or down the track weeks/months/years later, which trigger an emotional reaction due to the trauma of KD. It doesn't have to be anything specific, or even necessarily related to KD.

With the current COVID-19 situation creating a complexity of changes within our communities, it is only natural to experience worry, stress, anxiety, fear, or a multitude of other emotions! Everyone is different and for some people this will be minor, however for others it can be quite distressing and lead to further impact on one's day to day functioning.

Our kids may equally be experiencing emotional differences as well. Their world is changing too. Their education looks different. They can't interact with their friends in ways they are used to. There will be a whole lot of new experiences for everyone and new ways of working and schooling for many. Schools are preparing for distance learning and parents will be challenged to juggle working from home and educating their kids in ways never experienced before. All you can do is your best. Everyone is in the same boat. There are no rules or the best way to do this. It is uncharted waters for the education system too. You might find some of the tips in this document useful:

https://drive.google.com/open?id=1GfDzP63qrLFS99c_KGAGqLxAnYy5lkqQ

Please don't feel that you are alone. We are all here to support each other, so please reach out to our KD community, or if you prefer, access other supports that are available for yourself, your children, and your family. We not only need to look after our physical health at the moment, but our mental health as well which is just as vital.

For more information or further support:

- **Kawasaki Disease Foundation** <https://kdfoundation.org.au/>
- **Headtohealth** <https://headtohealth.gov.au/>
- **Lifeline Australia** <https://www.lifeline.org.au/> PHONE 13 11 1
- **Beyond Blue** <https://www.beyondblue.org.au/> PHONE 1300 224 636
- **Kids Helpline** <https://kidshelpline.com.au/> PHONE 1800 551 80
- **Mensline** <https://mensline.org.au/> PHONE 1300 78 99 78
- **Triple Zero** PHONE 000 (emergencies)
- **National Coronavirus Helpline** PHONE 1800 020 080
- **Helping Families Cope: National Child Traumatic Stress Network Factsheet**
https://www.nctsn.org/sites/default/files/resources/fact-sheet/outbreak_factsheet_1.pdf