FAQ for people with HLH in the UK during the CORONAVIRUS pandemic

Histio UK

Document Expires 01.08.20

WHAT IS CORONAVIRUS?

Coronaviruses are a large family of viruses (coronaviridae) which may cause illness in animals or humans. In humans, several coronaviruses are known to cause respiratory infections ranging from the common cold to more severe diseases such as Middle East Respiratory Syndrome (MERS) and Severe Acute Respiratory Syndrome (SARS). The most recently

discovered coronavirus causes coronavirus disease COVID-19

WHAT IS COVID-19?

medical attention.

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

WHAT ARE THE SYMPTOMS OF COVID-19?

The most common symptoms of COVID-19 are fever, tiredness, and dry cough. Some people may have aches and pains, nasal congestion, runny nose, sore throat or diarrhoea. 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

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Continuously updated information on Coronavirus can be found here https://www.gov.uk/coronavirus

HOW DOES COVID-19 SPREAD?

People can catch COVID-19 from other people who have the virus. The disease can spread from person to person through small droplets from the nose or mouth which are spread when a person with COVID-19 coughs or breathes out. These droplets land on objects and surfaces around the person. Other people can then catch COVID-19 by touching these objects or surfaces, then touching their eyes, nose or mouth. People can also catch COVID-19 if they breathe in droplets from a person with COVID-19 who coughs out or exhales droplets. This is why it is important to stay more than 2 metres (6 feet) away from a person who has symptoms.

HOW LONG DOES COVID-19 SURVIVE ON SURFACES?

It is not certain how long the virus that causes COVID-19 survives on surfaces, but it seems to behave like other coronaviruses. Studies suggest that coronaviruses (including preliminary information on the COVID-19 virus) may persist on surfaces for a few hours or up to several days. This may vary under different conditions (e.g. type of surface, temperature or humidity of the environment).

If you think a surface may be infected, clean it with simple disinfectant to kill the virus and protect yourself and others. Clean your hands with an alcohol-based hand rub or wash them with soap and water. Avoid touching your eyes, mouth, or nose.

WHAT CAN I DO TO LIMIT THE RISK OF BEING INFECTED BY COVID-19?

First and foremost, practice consistent, quality hand-washing. Every person in your home should be washing hands for at least 20 seconds, with soap and warm water. Wash after using the bathroom, before eating, as soon as you get home, after coughing or sneezing and regularly in-between.

Soap and water is the best way to wash, but if you don't have access to a sink, a hand sanitizer with alcohol content of at least 60% is a good alternative.

Next, cover coughs and sneezes. Teach your family to cough/sneeze into their elbows. Even small children can do this and they will be more likely to do it consistently if they see everyone else do it too. It is also important to teach and remind children not to touch their mouths, noses, or eyes.

It is good practice to also regularly disinfect high-touch surfaces in your home. Doorknobs, light switches, sink handles and counters/tables, are a good place to start. Disinfect cell phones and any tablets or game controllers that your children use regularly, as well.

HOW LONG IS THE INCUBATION PERIOD FOR COVID-19?

The "incubation period" means the time between catching the virus and beginning to have symptoms of the disease. Most estimates of the incubation period for COVID-19 range from 1-14 days, most commonly around five days. These estimates will be updated as more data becomes available.

IS THERE A VACCINE, DRUG OR TREATMENT FOR COVID-19?

Not yet. To date, there is no vaccine and no specific antiviral medicine to prevent or treat COVID-2019. However, those affected should receive care to relieve symptoms. People with serious illness should be hospitalized. Most patients recover thanks to supportive care; this means measures such as oxygen and fluids.

Possible vaccines and some specific drug treatments are under investigation. They are being tested through clinical trials. The World Health Organization is coordinating efforts to develop vaccines and medicines to prevent and treat COVID-19.

The most effective ways to protect yourself and others against COVID-19 are frequently cleaning your hands, covering your cough with the bend of elbow or tissue, and maintaining

a distance of at least 2 metres (6 feet) from people who are coughing or sneezing. (See 'what can I do to protect myself' above).

HOW DOES COVID-19 AFFECT PEOPLE WITH HLH?

HLH can be caused by a genetic problem (called primary HLH) or be triggered by another disease such as infection, cancer or rheumatology diseases (e.g. Stills Disease, systemic juvenile idiopathic arthritis and Systemic Lupus Erythematosus) when it is called secondary HLH. You can find more information about HLH here https://www.histiouk.org/wp-content/uploads/2020/04/HLH-Adult-and-Adolesent-Patients-brochure_a5_1-002.pdf and

https://www.histiouk.org/wp-content/uploads/2020/05/HLH-Children.pdf

How coronavirus may affect you depends on

- what type of HLH you have
- what treatment you are on

The medical team who look after your HLH will be able to advise you on this. One question you may have is 'should I be shielding?' and again this depends on your particular type of HLH and its treatment. More information on shielding can be found here:

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

For more general information visit:

World Health Organization website

https://www.who.int

European Centre for Disease Prevention and Control

https://www.ecdc.europa.eu/en

Public Health England

https://www.gov.uk/government/organisations/public-health-england

UK Government website

https://www.gov.uk/coronavirus