



COVID-19 AND SICKLE CELL DISEASE: WHAT YOU NEED TO KNOW

<https://www.youtube.com/watch?v=GfK9K-4MHkE&t=287s>

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Important links: www.sicklecellconsortium.org www.redcrossblood.org
www.sicklecelldisease.org www.OneSCDVoice.com
<https://covidsicklecell.org> www.cdc.gov/covid19



What is considered a high fever?

A fever in sickle cell disease is 101 degrees or higher.

The COVID-19 symptoms sound the same as acute chest. How do we know the difference?

Yes, the symptoms do mimic acute chest syndrome which is why medical advice is vital. Contact your doctor if you have a fever, shortness of breath or a cough. Sometimes ACS is accompanied by chest pain but not always. This is addressed and provided to the medical community on how to specifically identify ACS via calls. Guidelines are on the SCDA website as well. Provider guidelines complement the information provided to patients and caregivers.

Since this is a respiratory virus, how should those who use cannabis adjust their behavior to protect their lungs?

They should stop as anything inhaled is a bad idea. Anything inhaled can be an irritant to the lungs. If there are other ways to use cannabis other than inhalation is available, that would be a better option. (personal opinion)

What does an acute chest feel like?

Most complaints are chest pain different from usual pain crises and oftentimes have a cough. They do not always know that oxygen is low until examination. Usually chest pain, cough, and sometimes fever.

I am concerned about my daughter who has sickle cell trait. COVID-19 often results in pneumonia, should those with sickle cell trait be in the at-risk category?

As far as is known, there is not a reason to believe that sickle cell trait causes any serious risk of COVID-19 infection. However, there is a lot we do not know about sickle cell trait. (unofficial recommendation) practice what everyone across the globe is practicing including social distancing.

Some believe that anti-malaria drugs could be a treatment for COVID-19. As sickle cell trait provides protection from malaria. Your perspective?

There could be a link as sickle cell disease evolved as the trait was protective against severe infection of malaria. Don't believe there is an exact link. Defer the question for future discussion.

People hear malaria and think about the link between sickle cell trait and malaria. Whereas the discussion is about an anti-malaria drug, which targets when malaria attacks the red blood cell. Most of the drugs target the infection stage. However they are not connected to the same reason sickle cell is protective against malaria. The drug works differently, not in the same way the trait is protective. (Dr. Lakiea Bailey)

Do you have any specific advice for Trait Warriors?

Donate blood.

Are you aware of anyone in the sickle cell community who has been diagnosed with COVID-19.

Yes, a handful in various countries around the world. To my knowledge they have all done well, no one has died. There is a registry where the provider can document information about cases within the community. This enables providers across the world to see the difference in outcomes. Also, a measure for caregivers to provide what worked to help the individual get better.

There have been both sickle cell patients and caregivers who have been diagnosed with COVID-19.

I am in a home with an essential employee. How can she not expose her niece to the virus. Should she take steps to work from home?

Yes. Particularly if they live with someone who is at a higher risk. Some people cannot work from home, she could try to keep her distance within the home as much as possible. Many medical staff have family members who are at high risk. They have decided to be extra cautious in staying in a different room and sanitize the environment regularly.

How can you distinguish COVID-19 pain from SCD?

As far as we know, COVID-19 has not presented with pain. If you're having pain and COVID-19 symptoms, don't just assume it is a pain episode.

There are reports in some populations of individuals having some chest pain but not all over. It would be very different.

What are nutritional measures that could help strengthen the immune system to avoid the virus?

So far, we are not aware of diet to protect from infection. No data yet. Keep hydrated, good sleep, take meds as prescribed, stay warm.

Their son has just recovered from influenza and wants to know if he is more susceptible to COVID-19.

We are still in the tail-end of the influenza season. Many think they have COVID-19 when it is actually the flu which can be treated by some degree with pills. No data to support this, but having both at the same time could be worse. Be sure to get your flu shot to minimize chances of getting the flu.

If you test positive for COVID-19, can you be reinfected?

The typical virus, once you've been exposed to it your body develops an immune response that the next time you're exposed, you develop mild symptoms. We need to keep an eye out to see if people are being reinfected.

Is there a greater risk for those with ss genotype versus sc?

Not that I know of. That is why the registry is so important to share information abroad with sickle cell specialists to measure experiences across the board. All genotypes are at serious risk of having a serious illness from COVID-19.

Today Michigan was issued the stay at home lockdown. Several warriors are panicked whether to go to appointments to receive medicines. I am afraid they will be exposed to someone with COVID-19. What should they do?

View the SCDAAs recommendations where this is addressed. Every patient and clinical situation is different. If routine sickle cell visits can be turned into a telephone visit or electronic visit, then that is what is being recommended to providers/physicians. Schedule visits converted to phone visits. To eliminate any risk from being infected en route. As your medical team to call in prescriptions or call over the phone. There have been changes where the insurance company will pay the doctor's office for visits across the phone. This is a case-by-case basis. Ask your physician what is right for you.

CVS in many areas is offering prescriptions delivered free. Also private pharmacies are doing the same.

Is SCD considered special needs or clinical disability under normal circumstances and would entitle us to those arrangements for others?

Rephrased: Does living in a pandemic with sickle cell disease and the need to socially isolate entitle someone to disability benefits?

Some SCD patients meet the criteria for disability, not everyone. In the context of COVID-19, I would suggest if your provider's office has a social worker or connect with one of the SCD CBO, you may get help answering the question for your circumstance.

Is an x-ray helpful to see the virus in the chest or lung?

Yes, those types of tests are used to evaluate COVID-19. Doctors do use x-rays and CAT scans to treat people with COVID-19. There are dramatic changes that can be seen in the lungs which is why people have issues with cough and trouble breathing.

I have to go into the office daily and we are in cubicles, is there anything extra I need to do?

Yes, keep your distance from people at least 6 feet. If you use common surfaces, that is not a great idea. There needs to be workspace separation. Anything you have to share should be wiped down with something alcohol-based before you start. Request to work from home. Many places are instituting or mandating telework. Your company's human resources department or union representative (if you are in a union) to ask these kinds of questions to make your workspace as safe as possible.

What part of the world has the highest number of sickle cell disease persons with COVID-19?

We do not know yet. There has not been much in the way of COVID-19 with sickle cell patients. I do not have a sense of global impact. However, there are a couple reported in London. Many SCD patients have been hospitalized in the past few weeks where COVID-19 was being treated. The registry will be really important to provide reassurance. I have not heard of a lot of complications with COVID-19 and sickle cell disease but we will continue monitoring.

What happens to our lungs post COVID-19 recovery?

We do not have a lot of information. It seems lung function can be compromised. Some have a mild infection, not much in the way of symptoms. There is a variability just as with the common cold.

How would you treat a patient who tests positive for covid19 with a history of acute chest and stroke and no spleen?

Not having a spleen makes it harder to fight infection in anyone.

Regarding strokes, regular transfusions should be continued to prevent another stroke.

Anyone who has had acute chest syndrome (ACS) in the past should be on preventive treatment. Most experts consider patients who present positive with COVID-19 and a history of ACS to be at high risk for recurrence during a COVID-19 infection. Recommendations have been made to providers to be extra careful and vigilant in assessing the patient for any signs of developing ACS. They would be monitored more closely as there is concern that COVID-19 could make the development of ACS more likely.

What are the risks of a sickle cell patient being wrongly treated for COVID-19? During the swine flu outbreak, I was misdiagnosed, treated and almost died as a result.

Right now there is not a treatment for COVID-19. The treatment would be supporting the patient through it with such things as oxygen or ventilator if needed. We are not there yet where a drug is available to treat. There have not been any who have tested false positive.

How do you know if you are asymptomatic with COVID-19?

There is no way of knowing without symptoms unless you have been exposed to someone who tested positive with COVID-19. Another reason to call your healthcare provider if you've been exposed to be tested. As tests are limited, those who are asymptomatic may not be tested.

What is the average age of SCD patients tested positive for COVID-19?

There have been so few that I am aware of, I could not tell you. The ones I've heard of are in their 40's and 50's.

How do you treat restrictive lung disease alongside COVID-19?

That can be challenging. If someone has restrictive lung disease a really bad infection with COVID-19 would make it worse. The message we are stressing is to stay at home.

We often consider the worst-case scenario and how it impacts our families. Try your best not to get worried and panic. Try to avoid panic mode and maintain some degree of normalcy right now although we are not living in a normal way. Take this challenging moment to create something new, such as live concerts online. Create physical distancing without emotional or social distancing as we require more emotional support right now.

How should I deal with anxiety during the COVID-19 pandemic as people with sickle cell already have a slew of health problems?

Anxiety, depression and feeling of isolation will only get worse. There is a connection between mental and physical health. Just having sickle cell disease can be isolating in and of itself. We need to address this by having social experiences through the Consortium where we can see each other. Another idea is hosting watch parties in exchange for isolated streaming.

There's video chat and other ways to interact.

The Consortium has a few things scheduled and coming up such as warrior games and solving memories, escape room and other things to help with interaction and engagement. A lot of our meetings have been canceled in which we would get together to see each other or no longer happening.

I have clients with SCD who are just recovering from pneumonia with similar symptoms as COVID-19. If a client has similar symptoms as COVID-19 should they be tested? Is there a fee for testing?

MARAC and SCDA is advising anyone with symptoms of pneumonia to get tested. One of the key signs is a lung infection. If you have insurance as far as I know they are covering it. Unsure about those who do not have health insurance.

We are in a time where everything is about our health. If someone with sickle cell disease is uninsured and concerned about being tested, I urge you to call your local CBO via sicklecelldisease.org or call the national office as resources can be identified in your community and not make cost a barrier. The SCDA wants to be informed if cost is a barrier.

While the main concern is respiratory and lack of oxygen can affect the brain and those who have had meningitis with laden effects, how may COVID-19 further affect the brain?

I am not aware as it is still early on of the effects on the brain. If the brain does not get enough oxygen, in the case of really bad COVID-19, the brain could suffer. I am not aware of people who have recovered and experienced any long-lasting brain problems.

If you're at home mostly, should you still be wary about touching your face?

It is hard. As you are trying to make your home a protected environment with thorough cleaning it should be less of a problem as we are self-isolated. This becomes a problem when you're out of your home. Practice putting your phone on speaker instead of near your face.

A lot of sickle cell patients beyond transition-age do not have hematologists nor primary care physicians but seek treatment through the ER, and have been told to seek their doctors. What advice can you offer in the case of crisis?

Of course the ER is an option. There are community health centers across the country. Call local CBO to identify other resources to see if there are hematologists and primary care with experience who can offer care in your region. Oftentimes, the insurance company will identify preferred providers.

Any advice on how to completely isolate me from the family as we share everything (eating utensils etc.)?

It is better to change your own practices than those around you. This is a good opportunity for a family meeting to share what you've learned today about safety and health vulnerability. When using common spaces, take turns and ask the last person to wipe things down when done. A separate place to sleep if you share a room. In warmer areas, open windows to get fresh air. If there are ways to distance, do try. Practice regular hygiene when preparing meals with frequent handwashing.

I have appointments twice per week for iron overload and infusions. Should I request decreasing visits?

This is a case by case situation, including port flushes and apheresis which would request frequent visits. Contact your healthcare provider to see if there are any risks for missing or alternatives. Is the iron overload so bad that it is worth the risk of COVID-19 to receive infusions? This must be answered by your provider. "Where is the greater risk?" is the concept.

How are we defining fevers? I've heard that some people have fevers with COVID-19, others do not. How are we defining low-grade fever? What does it mean to have a fever? If we have symptoms of the flu should we self isolate until we know better?

A true fever is 101 or higher. If you're continuously checking fever and it is rising and you are not feeling well, call. Do not wait until you reach 101. Never ride out the flu at home if you have sickle cell disease as you are at high risk of a bad infection. Always get checked out as it could be something else or the beginnings of ACS.

Make sure you have a thermometer. Yes, you may have COVID-19 and no fever. Symptoms are fever, cough or shortness of breath. You could have only one symptom call your medical provider, even if you do not have a fever.



