

# Understanding Coronavirus and Cauda Equina Syndrome

Cauda Equina Foundation, Inc.

Medical Advisory and Review Board

March 17, 2020

James Wymer, MD<sup>1</sup>, Daniel W. Krichbaum, Pharm D<sup>2</sup>, Amanda Proctor, B.S.-RRT<sup>3</sup>

*1. University of Florida Comprehensive Spine Center, University of Florida Neuromedicine, Professor at University of Florida, Specialty in Neuromuscular disease diagnosis and management, Principal Investigator, Cauda Equina Foundation, Inc. Medical Advisory and Review Board*

*2. Pfizer, Inc. Senior Director, Team Leader Field Medical Director Group Inflammation & Immunology Team, North American Medical Affairs Principal Investigator, Cauda Equina Foundation, Inc. Medical Advisory and Review Board*

*3. Cauda Equina Foundation, Inc. Founder, President & CEO, Cauda Equina Foundation, Inc. Medical Advisory and Review Board Respiratory Therapy Clinical and Patient Educator, Sub-Investigator*

## Background

COVID-19 is a respiratory virus that in some individuals causes severe respiratory distress, respiratory failure, and possibly death. Data show that individuals with severe COVID-19 disease are typically over 60 years in age and/or have other underlying diseases or health problems that make having a respiratory virus a more severe illness. Most otherwise healthy individuals have mild symptoms and can recover at home. Some are infected but remain asymptomatic and are unaware that they are infected. These individuals are often out in the community as they are not ill and can contribute to the spread of the virus. Of additional importance, is that in the early stages of infection many do not feel ill yet are shedding virus.

Coronaviridae is a family of viruses that includes 4 species of coronavirus that cause some instances of the common cold as well as the species that cause Middle Eastern Respiratory Syndrome (MERS), Severe Acute Respiratory Syndrome (SARS), and now Coronavirus Disease 2019 (COVID-19). The virus that causes COVID-19 is SARS-CoV-2, and it is closely related to the SARS virus.<sup>3</sup> COVID-19, MERS, and SARS are all considered zoonotic diseases in that the reservoir for the virus is an animal and in this case the animal is a species of bat. The current theory is that the first animal to human transmission, also known as a spillover event, occurred in a seafood market in China which also sold live animals. The virus is well configured to infect humans and to be easily transmitted from human to human. These first infections in Wuhan, China were the beginning of the current worldwide COVID pandemic.<sup>9</sup> Viruses, such as COVID-19, do not respond to the antibiotics used to treat bacterial and fungal infections. Current antiviral drugs available to treat viruses such as Herpes Type 1, Hepatitis C, Influenza, and HIV are not effective against SARS-CoV-2. However, clinical trials of new anti-virals are being conducted to find one that fights SARS-CoV-2..

Unfortunately, there is no vaccine to prevent infection from SARS-CoV-2 as this is a novel virus. Due to the novelty of SARS-CoV-2, there is no natural immunity found in humans.<sup>6</sup> Therefore, this means that as a population we have no herd immunity to SARS-CoV-2. This lack of individual and herd immunity makes it easier for this virus to cause disease in humans and for this disease to be very contagious.<sup>6</sup> Additionally, amount of the virus that is being found within the nose and throat of infected individuals is quite high, making the amount of virus found in droplets from infected individuals higher. This increases the contagious nature of the virus.<sup>6</sup>

One study on how long viable virus survives on surfaces demonstrated that SARS-CoV-19 can live for many hours on plastic, some metals and other solid, non-porous surfaces. Recent data from the experience in China suggests the incubation period (time from exposure to symptom onset) to be 5 – 12 days, which supports the CDC recommendations of self-quarantine for 14 days after suspected exposure.

### ***What are the symptoms of COVID-19<sup>1,2,8</sup>***

Fever or chills  
Cough  
Shortness of breath or difficulty breathing)  
Gastrointestinal symptoms such as nausea, vomiting and diarrhea  
Muscle aches or body aches  
Fatigue  
Headache  
New loss of taste or smell  
Sore throat  
Congestion or runny nose

\*This is not all inclusive. Please consult your medical provider for any other symptoms that are severe or concerning.

### ***What are Emergency Symptoms of COVID-19<sup>1,2,8</sup>***

Difficulty breathing or shortness of breath  
Persistent pain or pressure in the chest  
new confusion, excessive sleepiness or inability to arouse  
Bluish lips or face

\*This is not all inclusive. Please consult your medical provider for any other symptoms that are severe or concerning. If you experience any of the emergency symptoms of COVID-19, call emergency services, 911 in the United States.

## **COVID-19 Spread**

Community spread is a term that has recently been discussed in the news, but what does it mean? Everyone is at risk for catching COVID-19, especially those that live in an area where there is documented community spread. Community spread means that the people who have been infected with a virus in a particular area cannot trace where or whom they came into contact with to cause an infection. Therefore, it is not known from where or from whom the sick individual was infected.<sup>10</sup> Individuals living in an area where there is community spread, are at a higher risk of becoming infected when out in the community.

### ***High Risk Populations for COVID-19***

There are individuals that are at a higher risk for more severe illness due to infection of COVID-19. Those individuals include people over age 60, those with underlying cardiovascular and/or lung diseases, diabetes, autoimmune disease, immunosuppression, cancer, severe chronic diseases/illnesses, and those taking immunosuppressants and/or some biologic medications.<sup>1</sup>

In the most recent report from China, those patients that had chronic illness between the ages of 30-69 had a 19% rate of admission to critical care services when infected, though this number may change as more individuals are tested and more cases are reported.<sup>1</sup> Those with the highest fatality rate included people with cardiovascular disease, diabetes, respiratory disease, and cancer.<sup>1</sup>

### ***Are Cauda Equina Syndrome Patients at a higher risk for severe COVID-19?***

Cauda equina syndrome is a collection of symptoms that arise due to injury of the cauda equina in which there is an acute phase and a chronic phase and varying levels of severity. Chronic CES (Ch-CES) seems to affect the entire body over time, and many patients have reported co-morbidities that did not present until after diagnosis of Ch-CES. Such co-morbidities that have been reported include ankylosing spondylitis, Behcet's disease, Multiple Sclerosis, Systemic Lupus Erythematosus, Sjogren's, and other autoimmune diseases. Other underlying diseases that are commonly reported include diabetes, cardiovascular disease such as high blood pressure, vascular diseases, autonomic nervous system disorders such as autonomic dysautonomia, and obesity. It is important to note these are patient reported co-morbidities and are not yet confirmed by research. Certainly, many of these diseases occur due to exposure to risk factors such as cigarette smoking, obesity and other exposures. We do not know if these comorbidities are related to chronic CES. All of these co-morbidities may increase the risk of having a severe case when infected with COVID-19.

In addition to the patient reported comorbidities of individuals with CES, some patients have also reported more severe symptoms and complications from colds and flu, increased symptoms of chronic cauda equina syndrome (Ch-CES), and prolonged illness and recovery from colds and flu. For these reasons, it is believed that there is a real concern that COVID-19 has the potential to be severe in some of Ch-CES patients. Please remember that each patient is unique and may experience different outcomes from this infection.

Further, Ch-CES causes disability in many and that leads to a limited or decreased mobility to varying degrees and severity, in some cases those with Ch-CES are bedridden. In individuals with limited or decreased mobility there is an increased risk of developing pneumonia due to decreased deep breathing on a regular basis. This may further increase the risk of those with Ch-CES to develop pneumonia from COVID-19. Some COVID-19 infections may experience viral pneumonia as well as a secondary infection with bacteria that causes pneumonia. (i.e. a more severe case of COVID-19).

Due to these concerns it is recommended that individuals with Ch-CES follow the guidelines set by the [CDC](#) regarding “high risk” individuals. We also recommend that you check your local county government web site to see what further restrictions they are requiring in addition to those required by the federal government.

#### **Current CDC recommendations for high risk populations include:**

- *Have supplies on hand<sup>2</sup>*
  - Consider having a family member or friend gather supplies for you and/or pre-order them to be ready for pick up at the store to limit your loved one’s exposure in a crowded store. There are also several grocery delivery companies, consider having them delivered to you. If you have trouble cooking or preparing meals, look into [Mealtrain](#) or other such sites in which your family and friends can sign up for certain days to bring you a meal.
  - Go to [ready.gov](#) for a list of recommended supplies to have on hand for periods of prolonged times at home during emergencies
  - Remember to have something to do at home during this time of shutdown, crafts, games, movies, books
- *Have enough medication on hand to last through any prolonged stays at home<sup>2</sup>*
  - Contact your healthcare provider to ask about obtaining extra necessary medications to have on hand in case there is an outbreak of COVID-19 in your community and you need to stay home for a prolonged period of time.
  - Having extra medication of controlled substances may not be possible so work with your providers to ensure you do not run out in the event your doctor’s office is closed due to the virus spreading in your area; have a plan now.
  - If you cannot get extra medications, call your insurance company. Many are overriding the time limit on refills given the current national emergency.

- Call your insurance company to ask them what companies you can use for mail order to make it easier for you if you should need them later. There may be longer waits on phone lines later, so get the information now. Transferring to mail order early may help with wait times and give you time to sort out transferring medications before it is too busy.
- Consider using pharmacies that have drive-throughs. Once you have signed everything and have your medication in your car, wash your hands with hand sanitizer.
- Be sure you have over-the-counter medicines and medical supplies (tissues, etc.) to treat fever and other symptoms.
  - Most people will be able to recover from COVID-19 at home. Talk to your physician about what over the counter medications you can take at home in the event you get sick.
- Talk to your doctor about your health and any specific uses of over the counter medications.
- Some medications are experiencing supply shortages due to increased demand, if a medication you are taking is not available talk to your doctor about medication substitutions.
- Your doctor may make a plan for you in case you get sick or have complications from your chronic illness for example:
  - Having you call the office if you get sick so they can direct admit you to the hospital, so you are not exposed to illnesses in the emergency department. Be sure to discuss emergency symptoms for your individual medical condition(s) to watch for and have a plan.
  - Some physicians are providing patients with as needed medications to have at home to prevent the need for emergency room visits. Talk to your doctor about emergency medications to have on hand, when and how they should be used, and when to seek emergency care.
- Share your plan information with a caregiver, family, or friend.
- Discuss telemedicine options for routine and sick visits with your physician to limit exposure to COVID-19.
- *Have enough household items and groceries on hand so that you will be prepared to stay at home for a minimum of two weeks<sup>2</sup>*
  - Be sure to have nutritious foods to keep yourself healthy
  - Ensure that you have cleaning products as well as soap for handwashing
    - If you cannot find cleaning products for surfaces go to the [CDC's website](#) for an alternative cleaning product
    - For more tips on cleaning go to the [CDC's website](#)
- *Take every day precautions<sup>2</sup>*
  - Avoid close contact with people who are sick
    - Avoid being within 6 feet of infected individuals. If at all possible, avoid contact with anyone sick.
    - Stay a minimum of 6 feet (2 meters) away from individuals who are not showing signs of illness

- Take everyday preventive actions<sup>2</sup>
  - Clean your hands often with soap and water
    - Before you touch your face, eat, brush your teeth, touch eyeglasses, scratch your nose, put on make-up, do your hair. If your hands are going towards your head or face, wash your hands first.
  - Wash your hands often with soap and water for at least 20 seconds, especially after blowing your nose, coughing, or sneezing, or having been in a public place.<sup>2</sup> Sing “Happy Birthday” to yourself twice.
  - Wash your hands as soon as you enter your home, then clean your doorknob and anything else you touched before washing your hands including the handle of the sink faucet, then rewash your hands with soap and water.
  - If soap and water are not available, use a hand sanitizer that contains at least 60% alcohol.<sup>2</sup> Be sure to rub it in until it is completely dry otherwise it has not had time to work.
  - To the extent possible, avoid touching high-touch surfaces in public places – elevator buttons, door handles, handrails, shaking hands with people, shared pens, etc. Use a tissue or your sleeve to cover your hand or finger if you must touch something that others commonly touch.
  - Carry disinfecting wet wipes with you to disinfect objects like shopping carts or anything you have to touch for prolonged periods of time.
- Wash your hands after touching surfaces in public places.
  - Avoid touching your face, nose, eyes, etc.
- Clean and disinfect your home to remove germs: practice routine cleaning of frequently touched surfaces for example: tables, doorknobs, light switches, handles, desks, toilets, faucets, sinks, cell phones, tablets, remote controls
  - Clean your assistive devices, especially where your hands touch the device, especially in public.
    - Clean the device after using the restroom, before eating, before touching your face, or doing anything where your hands are near or touching your face
      - Wash your hands before and after cleaning your assistive devices
    - Per the CDC, to disinfect surfaces using bleach, dilute 5 tablespoons to 1 gallon of water or 4 teaspoons bleach to 1 quart of water,
    - if you use alcohol to disinfect surfaces it must be 70% concentration to be effective.<sup>11</sup> Hand sanitizer that is 60% alcohol will not be sufficient.<sup>11</sup>
- Avoid crowds, especially in poorly ventilated spaces.<sup>2</sup> Your risk of exposure to respiratory viruses like COVID-19 may increase in crowded, closed-in settings with little air circulation if there are people in the crowd who are sick.<sup>10</sup>

- This includes conventions, concerts, movie theaters, amusement parks, malls, public transportation (subways/metros, buses), religious gatherings and other places where large crowds gather
  - Avoid all non-essential travel including plane trips and cruise ships.<sup>2</sup>
- *If COVID-19 is spreading in your community, take extra measures to put distance between yourself and other people to further reduce your risk of being exposed to this new virus.*
  - *Stay home as much as possible.*
    - Consider ways of getting food brought to your house through family, social, or commercial networks such as [Mealtrain](#)
- *Have a plan for if you get sick:<sup>2</sup>*
  - Consult with your health care provider for more information about monitoring your health for symptoms suggestive of COVID-19
  - Stay in touch with others by phone, email or video chat. You may need to ask for help from friends, family, neighbors, or community health workers if you become sick.
  - Determine who can provide you with care if your caregiver gets sick
  - Have all of your medications and supplements written down and easily accessible, include name of medication, dosage, and frequency. If you can't take the generic form of a medication, write down why.
  - Get copies of your medical records to have available in case of emergency, it is very helpful for physicians that do not know you to have your medical records to be able to take care of you
  - If you have a hard time getting your records write down your health history and the names, numbers, and addresses of all of your doctors. You can then work on obtaining your health records. If you still have trouble contact the [Department of Health and Human Services](#).
  - Write down anything that a healthcare provider needs to know about you and your care such as allergies or special precautions in your care.
  - If you have a medical implant, write down the company name, phone number, device type, and serial number for the implant. If you don't have this information, give the company a call or talk to the doctor that implanted it.
  - Be sure to designate a medical proxy or write up a living will or [advance directive](#).
  - Make sure your caregiver knows who your next of kin is and how to get in contact with them, write it down for your care providers as well.
  - Write down where to find your advanced directives, any power of attorney, and/or emergency contacts, or important documents.
  - Keep a "go" bag in the event you need to go to the emergency room or hospital suddenly with things that make you more comfortable for your stay (extra warm socks, pajama pants, undergarments, toiletries, dry shampoo, extra chargers for electronics, copies of your medical records, medication list, advance directives.) This is good practice even when there is no pandemic.

- If you end up in the emergency room, all of your providers should be made aware of it as soon as possible

This is not a complete list and is not a one size fits all list, each individual with CES has his or her own needs. Be sure to discuss individual patient needs with your healthcare providers and caregivers.

### **What do I do if I develop symptoms of COVID-19?**

- *If you feel like you are developing symptoms, call your doctor right away.*
  - Call your insurance company now, before you may become sick or visit their website to see if your insurance covers a telemedicine visit with your providers.
  - If you do not have insurance, call your local health department or local COVID-19 hotline for directions on how to get care in the event you get sick.
  - If you have [emergency symptoms](#) call 911 in the United states or use your countries emergency services number
  - **DO NOT** drive yourself to the emergency department
  - **CALL EMERGENCY SERVICES FOR SEVERE COVID-19 SYMPTOMS**

### **What do I do if I need to go to the doctor or hospital for something other than COVID-19?**

- Your doctor may not see you in the office due to risk of infection of COVID-19, so even if you are not having symptoms of COVID-19 and need to be seen for your other healthcare needs, call your doctor before going into the office for direction as they may have telemedicine options or other procedures in place for you to be seen
- If you have an upcoming appointment and you are worried about exposure to COVID-19 call your doctor's office and discuss your concerns with them before you cancel your appointment. Be sure to ask about telemedicine options.
- If you have an emergency due to your other healthcare needs and you are being driven in by a caregiver/friend/family, call the emergency department on your way there and ask for guidance they may have a separate entrance for non-COVID-19 patients. Some hospitals are not taking patients with non-Covid-19 emergencies and are diverting those patients to other hospitals. In addition to the arrival procedures, know which hospital you should go to in the event of an emergency. If you have a severe emergency call 911 or the emergency service number in your country.
- If you are being taken to the hospital by ambulance, the EMS workers will know where to take you to decrease exposures
- If you are hospitalized for something other than COVID-19 know that hospitals work very hard to reduce the spread of infection in their hospitals. If you have concerns about exposure risk to infectious disease, talk to your hospital healthcare providers.
- It's okay to ask a healthcare provider or member of the hospital staff to wash their hands upon entering your room, handling your food/belongings, or providing direct care to you.



## Other tips for COVID-19

1. Be sure that you have enough medical supplies and make sure your caregivers know how to order more for you in case you get sick. Write down the names and numbers of your medical supply companies, and either write down the name and/or item/model numbers of your supplies or take pictures of them and send them to your caregiver(s).
2. Be sure to take all medications that you are prescribed exactly as directed by your doctor and do not stop taking them without talking to your doctor or pharmacist first. If you have concerns about them compromising your immune system talk to your doctor or pharmacist before you stop your medications.
3. Some individuals with compromised immune systems were advised to wear masks before the COVID-19 pandemic, talk to your doctor to determine if this is still recommended for you at this time. If you are advised to wear a mask in public, follow the recommendations of the [World Health Organization](#). Remember to treat the mask like it is a part of your face to decrease contamination, don't touch it unless you wash your hands first.
4. WASH THOSE HANDS.
5. DON'T TOUCH YOUR FACE
6. Using virtual calls to keep in contact with your friends and family may decrease isolation
7. Play games on a virtual call, or play multi-player games online to decrease isolation
8. Be sure to keep active and get some exercise as recommended by your physician
9. To further decrease isolation, Cauda Equina Foundation is working towards providing a way for our members to have interaction with each other in small groups virtually. This will take some time to become available, we will let you know when it is live.

# Questions and Answers Coronavirus-19 (COVID-19) & Cauda Equina Syndrome (CES)

## 1. *Does having CES increase my risk of getting COVID-19?*

- a. Potentially, having chronic CES alone does not increase your risk of getting infected by COVID-19. CES is a collection of symptoms that arise due to injury to the cauda equina; CES is a neurological condition. CES does not typically decrease the immune system response, though there are a few instances in which it is possible such as CES due to cancers. The underlying cause of your CES

could place you at risk. Ch-CES does produce a disability that can reduce mobility and put those individuals at increased risk of significant complications due to infections and increased risk of developing pneumonia, but CES does not directly cause increased risk of becoming infected with COVID-19.

- b. Practicing proper hygiene can play a factor in decreasing the risk of infection and may decrease the risk of getting COVID-19, this includes practicing social distancing, hand washing with soap and water or hand sanitizer that contains 60% or more alcohol, exercise, respiratory breathing exercises, and keeping your environment clean.
- c. Individuals on medications that reduce your immune response have increased risk for becoming infected with COVID-19 as well as increased risk of serious complications. Talk to your doctor regarding your individual risks of immunosuppression and risk of contracting COVID-19

2. *Will my symptoms be worse if I have chronic CES and COVID-19?*

- a. It is impossible to determine each individual's reaction to COVID-19, however, there is an increased risk of serious complications and increased severity of illness if an individual has Ch-CES and gets sick with COVID-19. Ch-CES decreases mobility and that reduce mobility increases the risk of severe respiratory illnesses due to shallower breathing while laying down and other breathing mechanisms that are associated with decreased mobility.
- b. Decreased mobility also increases the risk of cardiovascular disease and obesity which are also risk factors for severity of COVID-19 symptoms in chronically ill individuals.

3. *What precautions should you take if you must go out in public?*

- a. Follow the [CDC](#) guidelines for limiting contact and exposure with social distancing and isolation, frequent handwashing with soap and water or hand sanitizer containing 60% alcohol, and not touching your face.
- b. Wear a mask that that covers both your nose and your mouth as recommended by the [CDC](#). Wash your hands before and after putting on and taking off the mask. Touch only the ties or earpieces to take on and off the mask. Treat the mask as an extension of your face and do not touch the mask with your hands. For more information on masks visit the [CDC's](#) website.

4. *Is 1:4 vinegar a safe disinfectant solution for surfaces?*

No, it is not. According to the [CDC](#) cleaning and disinfection guidelines, surfaces should be cleaned with either diluted bleach, or products such as Lysol, Clorox wipes, and hydrogen peroxide wipes and sprays. You can find a list of approved products from the [EPA](#).

When cleaning your medical equipment, please consult your equipment supplier or the user guide that came with your equipment. Keep a list of your medical device suppliers readily available.

5. *Will drinking bleach kill bacteria in my throat?*

**NO. DO NOT DRINK BLEACH OR ANY OTHER DISINFECTANT PRODUCT TO PREVENT NOR TREAT COVID-19 INFECTION.** It will cause serious irreversible harm to your body and may even cause death.

6. *What do I do if I have a sore throat?*

A sore throat can have a lot of different causes from allergies, acid reflux, to bacterial and other viral infections. Call your health care provider to discuss your symptoms.

7. *Will swimming in a hot tub or soaking in a hot bath heat up my body temperature enough to prevent COVID-19 and kill off the virus?*

This is not recommended by the CDC to kill or prevent COVID-19. Furthermore, prolonged soaking in hot water is not recommended as it may cause health risks to some individuals. Do not use a hot tub or soak in hot water without consulting your physician.

8. *Should I wear a mask if I was told to wear a mask for my medical diagnosis, they say it will cause me to get COVID-19 more easily?*

- a. Currently, it is recommended by the [CDC](#) for individuals with pre-existing health conditions or in the high risk population to practice social distancing and social isolation.
- b. According to the [World Health Organization](#), a standard mask won't protect against infection of COVID-19.<sup>12</sup> However, masks have been shown to decrease the spread of COVID-19 by decreasing the droplets expelled from individuals that are COVID-19 positive.<sup>16</sup> Some COVID-19 positive individuals do not have symptoms but can still spread the virus through droplets expelled through breathing, sneezing, coughing, talking, laughing, and singing.<sup>16</sup> Additionally, those that are COVID-19 positive can spread the virus through droplets before they develop symptoms.<sup>16</sup> Wearing a mask can help reduce the spread of the virus by individuals that are unaware that they have COVID-19.<sup>16</sup>
- c. Talk to your doctor about your individual risks of contracting COVID-19 and any additional prevention measures you may need.
- d. While wearing a mask or cloth face covering, treat it like is a part of your face, keep your hands off of it. Talk to your doctor about the best way to take it on and off, be sure to wash your hands. If you need further guidance the [World Health Organization](#) and the [Centers for Disease Control](#) are good resources.

9. *How serious is this, is it just getting blown out of proportion? Ebola killed almost 100% of people and no one freaked out about that like this.*
- No, this is not getting blown out of proportion. This is a pandemic, with severe impact throughout the world.
  - As you have heard on the news, all of these protection measures, social distancing, handwashing, and even curfews in some locations are to limit the risk and spread of infection so as not to overwhelm the healthcare system. This will also provide more time for the healthcare system in the US to be prepared for large numbers of patients with illness requiring hospitalizations and critical care. When protections are put in place early the system works the way it is supposed to.
  - The virus that causes Ebola is very different in the type of contact required for transmission from SARS-CoV-2. Ebola was contained very quickly before it spread to other parts of Africa and as well as the world.
10. *Is antibacterial soap more helpful than regular soap?*
- Handwashing with any type of soap is important
11. *How do I know if I have allergies or COVID-19?*
- Unfortunately, it is prime allergy season. Seasonal allergies can cause itchy and watery eyes, runny and stuffy nose, sore throat, and sneezing. These things can usually be treated with over the counter medications, with the advice of your doctor.
  - COVID-19 symptoms include cough, fever, difficulty breathing and shortness of breath, loss of taste and smell, headaches, body and muscle aches, gastrointestinal symptoms such as nausea, vomiting, and diarrhea, fatigue, sore throat, runny nose and congestion.<sup>8</sup>
  - If you have any symptoms of illness or you suspect you may have COVID-19 call your doctor right away to get tested as early intervention may decrease the risk of complications.
  - Follow the [CDC](#) guidelines for what to do if you become ill during the COVID-19 pandemic.
12. *How long should you stay at home?*
- This is region specific so follow the recommendations of the [CDC](#) and your local government. According to the [CDC](#), as a high risk patient you should always be prepared for an emergency.
13. *When should our prep be done by? When does the isolation start?*
- This is region specific so follow the recommendations of the [CDC](#) and your local government. According to the [CDC](#), as a high risk patient you should always be prepared for an emergency.

*14. What do I do about pain medication supply during emergencies?*

- a. Contact your physician to talk to them about an emergency plan for all of your medications, not just your pain medications. If you have difficulty obtaining your medications, contact your pharmacist and insurance company. Many states have new laws to help you maintain your medical supplies and medications in emergencies. Some insurance companies have programs where they assign a case worker, usually a nurse, to help navigate your care. Call your insurance company to see if you qualify for any of their support programs.

*15. How long does COVID-19 live on surfaces soft vs hard, and air?*

- a. It is not known at this time how long COVID-19 lives on surfaces.<sup>10</sup> Be sure to frequently wash your hands, clean and disinfect commonly touched surfaces.
- b. It is not known at this time how long COVID-19 survives in the air in one study it stayed alive for 30 minutes, but this is still being investigated. Social distancing and limiting exposure are recommended by the [CDC](#) especially for those in high risk populations and their primary caregivers.

*16. Should I drink vinegar to prevent COVID-19?*

- a. There is no evidence that it will prevent or treat COVID-19.

*17. Will my medication put me at a higher risk for complications if I get sick with COVID-19?*

- a. According to the [CDC](#) anyone with chronic conditions will have an increased risk for complications and serious illness and/or death from COVID-19, talk to physician about your individual risk.
- b. Some medications used to treat autoimmune disease (and some other chronic conditions) decrease the immune system; some of these medications will increase your risk of getting a serious infection, including from COVID-19. Some of these medications are being investigated as a treatment. Talk to your physician or pharmacist about the medications you take to determine your individual risk.

*18. I have an autoimmune disease and chronic CES, am in the high risk category for COVID-19?*

- a. According to the [CDC](#) anyone with chronic conditions will have an increased risk for complications and serious illness and/or death from COVID-19, talk to physician about your individual risk.
- b. Some medications used to treat autoimmune disease (and some other chronic conditions) decrease the immune system; some of these medications will increase your risk of getting a serious infection, including from COVID-19. Talk to your physician or pharmacist about the medications you take to determine your individual risk.

*19. I'm a caregiver of someone with Chronic CES, should I be going out in public and coming home to take care of them?*

- a. If you are primary caregiver for at-risk person(s) you also should be limiting your exposure and risks to COVID-19 to decrease the risk of exposing the individual you are caring for to COVID-19.

*20. What should I take at home if I get sick?*

- a. If you get sick at home and think it may be due to COVID19, call your physician right away to get tested and treated as early intervention may decrease your risk of severity.
- b. Talk to your doctor or pharmacist before you start taking any over the counter medications if you have a chronic illness or if you are already taking other medications.
- c. Make sure you are staying hydrated by drinking plenty of fluids.

*21. How do I get things I need when I can't go out?*

- a. Ask a friend, neighbor, relative to pick things up at the store for you. They can drop off items on your doorstep.
- b. If you must go out, you can limit your exposure with pre-order pick up, wash your hands, don't touch your face, use drive through or mail order pharmacies when possible, use mail order for household items, disinfect surfaces that are frequently touched, use a tissue as a barrier between your hands and things that are touched by others. Wear a mask as recommended by the CDC.<sup>16</sup>

*22. Is CES a chronic illness, injury, or disease?*

- a. Cauda Equina Syndrome is a collection of neurological symptoms that are the result of injury to the nerve roots at the base of the spine (the cauda equina). This injury of the cauda equina region can have different causes including compression, infection, cancer, spinal stroke, surgical errors, and trauma, just to name a few.
- b. Acute cauda equina syndrome (A-CES) is the initial point of injury to the cauda equina. It is an emergency that requires treatment ideally within 24 hours of onset of symptoms. If it has been longer than 24 hours from the onset of symptoms, the injury will be more difficult to recover from. Treatment is still recommended to be done as soon as possible if the injury is considered to be incomplete cauda equina syndrome (I-CES).
- c. Incomplete cauda equina syndrome (I-CES) is currently defined as injury to the cauda equina in which the patient experiences bladder dysfunction but not incontinence.
- d. Complete cauda equina syndrome (C-CES or R-CES) is catastrophic injury to the cauda equina in which the patient has overflow incontinence. Not all patients that are diagnosed with C-CES are treated surgically as currently there is no evidence of benefit in literature.

- e. Patients with Acute I-CES that have been treated and with sufficient time may show some recovery. I-CES may not fully recover and people may continue to experience neurological deficits and other symptoms related to cauda equina syndrome. This is classified as chronic cauda equina syndrome (Ch-CES).
- f. Patients with C-CES, whether they have been treated or not, will usually be diagnosed with Ch-CES. There are rare cases of full recovery in patients that presented with C-CES.
- g. Chronic Cauda Equina Syndrome (Ch-CES) is a chronic illness that results from injury to the nerve roots in the cauda equina region that results in disability due to a multitude of individualized symptoms ranging from chronic pain or intractable pain, bladder and/or bowel dysfunction, foot drop, leg weakness, sexual dysfunction, unsteady gait, poor circulation in the lower extremities, poor temperature control of the lower extremities, decreased skin integrity in the lower extremities and saddle region, pain and numbness in the saddle region, abnormal reflexes, chronic urinary tract infections, chronic and/or intractable constipation, neuropathy, spasticity, and radiculopathy. This is not a complete list of symptoms and disorders associated with Ch-CES and of note all of the listed symptoms are those most commonly reported by patients, in no particular order.

## Reference

1. Centers for Disease Control. *Interim Clinical Guidance for Management of Patients with Confirmed Coronavirus Disease (COVID-19)*. March 7, 2020. <https://www.cdc.gov/coronavirus/2019-ncov/hcp/faq.html>
  2. Centers for Disease Control. *If you are at Higher Risk*. March 12, 2020. [https://www.cdc.gov/coronavirus/2019-ncov/specific-groups/high-risk-complications.html?CDC\\_AA\\_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2F2019-ncov%2Fhigh-risk%2Fhigh-risk-complications.html](https://www.cdc.gov/coronavirus/2019-ncov/specific-groups/high-risk-complications.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2F2019-ncov%2Fhigh-risk%2Fhigh-risk-complications.html)
  3. World Health Organization. *Q & A on coronaviruses (COVID-19)*. March 8, 2020. <https://www.who.int/news-room/q-a-detail/q-a-coronaviruses>
  4. Fan, Jingchun, et al. "Early Release-Epidemiology of 2019 Novel Coronavirus Disease-19 in Gansu Province, China, 2020."
  5. Center for Disease Control. *What You Should Know About the Flu Antiviral Drugs*. April 2019. <https://www.cdc.gov/flu/treatment/whatyoushould.htm>
  6. National Health Counsel. *NHC Weekly Webinar Series on Organizational Impacts for Members Only*. March 13, 2020. <https://nationalhealthcouncil.org/issue/covid-19/>
  7. Chen, Chen, and Bin Zhao. "Makeshift hospitals for COVID-19 patients: where health-care workers and patients need sufficient ventilation for more protection." *Journal of Hospital Infection* (2020).
  8. Centers for Disease Control. *Symptoms*. May 13, 2020 <https://www.cdc.gov/coronavirus/2019-ncov/symptoms-testing/symptoms.html>
  9. Centers for Disease Control. *Situation Summery*. March 15, 2020 <https://www.cdc.gov/coronavirus/2019-nCoV/summary.html>
  10. Centers for Disease Control. *How it Spreads*. March 4, 2020. <https://www.cdc.gov/coronavirus/2019-ncov/prepare/transmission.html>
  11. Centers for Disease Control. *Clean & Disinfect Interim Recommendations for US Households with Suspected/Confirmed Coronavirus Disease 2019*. March 6, 2020. [https://www.cdc.gov/coronavirus/2019-ncov/prepare/cleaning-disinfection.html?CDC\\_AA\\_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2F2019-ncov%2Fcommunity%2Fhome%2Fcleaning-disinfection.html](https://www.cdc.gov/coronavirus/2019-ncov/prepare/cleaning-disinfection.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2F2019-ncov%2Fcommunity%2Fhome%2Fcleaning-disinfection.html)
  12. World Health Organization. *Coronavirus disease (COVID-19) advice for the public: When and how to use masks*. 2020. <https://www.who.int/emergencies/diseases/novel-coronavirus-2019/advice-for-public/when-and-how-to-use-masks>
  13. National Institute of Health. *Advance Care Planning: Healthcare Directives*. January 2018. <https://www.nia.nih.gov/health/advance-care-planning-healthcare-directives>
  14. Department of Homeland Security. *Ready: Before a Pandemic*. March 13, 2020. <https://www.ready.gov/pandemic>
  15. Department of Health and Human Services. *Health Information Privacy: Your Medical Records*. January 31, 2020. <https://www.hhs.gov/hipaa/for-individuals/medical-records/index.html>
- Centers for Disease Control. *About Cloth Face Coverings*. May 22, 2020. <https://www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/about-face-coverings.html>