

DSN COVID-19 Statement

April 8, 2020

The Dysautonomia Support Network recognizes the tremendous impact that the pandemic COVID-19 continues to have around the world. We have all become acutely aware of society's interconnectedness and our responsibility to take actions to protect one other. In order to assist you in making the best decisions for your sake and others, we would like to provide some educative resources to support you during this time of uncertainty.

Please be aware that this is a developing situation, so local and national recommendations may change day to day. Therefore, we advise that you routinely check with your local health department to ensure you are taking proper precautions. This statement will periodically be updated with changes, so please note the date at the top of this page.

We highly encourage you to contact your medical providers to discuss if you are at risk and what, if any, preventative measures you need to take. Because your provider is familiar with your unique history, they should be able to give the most insight into precautions you should observe.

What is COVID-19?

The term "coronavirus" refers to a type of infectious virus. Different strains can cause a variety of illnesses including the common cold, Middle East respiratory syndrome (MERS-CoV), severe acute respiratory syndrome (SARS-CoV), and other viruses.

In December 2019 a new strain of coronavirus appeared in Wuhan, China called the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). It is also called **Coronavirus Disease 2019** (COVID-19). It continues to spread from person-to-person throughout the world at a rapid pace. On March 11, 2020 the World Health Organization declared COVID-19 a global pandemic. There is currently no specific treatment or vaccine. The best ways to prevent the spread of coronavirus are with good hygiene and social distancing.

Common symptoms include fever, fatigue, a dry cough, a sore throat, chest pain, shortness of breath, etc. For most people the symptoms will be mild, but there is a risk of developing serious illness or even death. The risk of serious complications is higher for those in vulnerable populations, including those over the age of 60 and those with underlying conditions.

[World Health Organization \(WHO\)- What is COVID-19](#)
[Center for Disease Control \(CDC\)- COVID-19 Factsheet](#)

[Institute for Health Metrics and Evaluation \(IHME\)- COVID-19 Projections](#)

[John Hopkins- COVID-19 Global Map](#)

What to do if you become sick?

If you or a loved one have a fever, cough, or difficulty breathing please follow the recommendations of your local health department and your physician. Many countries, states, localities, and hospitals have set up dedicated COVID-19 hotlines that you may call to ask for more detailed and location specific information. Most people with COVID-19 do not require intensive care and can recover at home while following their doctor's instructions. However, if you are sick it is better to seek care as soon as possible to minimize the risk to yourself and others.

The following information includes the official [recommendations of the CDC](#):

Do not go to work, school, or other public places. Before going to any medical facility, please telephone them first to ensure that they can take proper precautions to prepare for your arrival. Unless you are in acute distress, you should telephone your physician from home first.

Your physician will ask about your symptoms, if you have travelled internationally recently, and if you have come into contact with a confirmed COVID-19 patient. After determining your risk your physician will give you instructions on what to do next. They may ask you to continue monitoring your condition from home, visit their office for further evaluation, visit a testing center, or proceed to an emergency department.

The CDC also has an online [Coronavirus Self-Checker](#) "to help you make decisions about seeking appropriate medical care", but ideally your physician should be your first point of contact.

Remember, if someone in your household has been diagnosed with COVID-19 then all residents must quarantine themselves at home.

Who is most vulnerable to COVID-19?

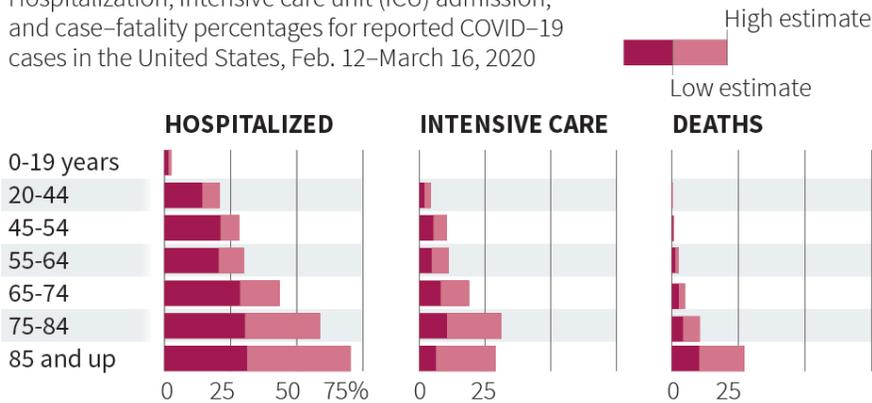
There are some underlying illnesses and situations that make individuals more vulnerable to COVID-19 by increasing the likelihood that they become infected and/or making it more difficult for their body to fight the infection and recover.

The group most vulnerable to COVID-19 are individuals [over the age of 65](#), especially those with health conditions. In all affected areas, COVID-19 mortality rates rise with age. According to the CDC, in the United States 8 in 10 COVID-10 deaths have been adults 65 or older. It is important to note that even elders who were in good health have fallen victim to the virus. Therefore, all elders and their loved

ones must remain vigilant. Please see the ["Older Adults" section on the CDC website](#) for more information and resources.

Severity by age group in the U.S.

Hospitalization, intensive care unit (ICU) admission, and case-fatality percentages for reported COVID-19 cases in the United States, Feb. 12–March 16, 2020



Source: Centers for Disease Control and Prevention

Staff, 19/03/2020

REUTERS

The following list is compiled from [CDC](#) and [NHS](#) guidelines identifying illnesses and situations that cause an increased risk of severe illness resulting from COVID-19:

- [Over the age of 65](#)
- Living in a nursing home or long-term care facility
- [Current pregnancy and breastfeeding mothers](#)
- Severe obesity (BMI ≥ 40)
- Endocrine disorders such as diabetes
- Heart disease
- Kidney disease
- Liver disease
- [HIV](#)
- Taking immunosuppressants
- Serious lung diseases including all cystic fibrosis, [severe asthma](#), severe COPD, etc.
- Solid organ transplant recipients
- Specific cancers situations
 - Blood or bone marrow cancers such as leukemia, lymphoma, or myeloma
 - Underwent bone marrow or stem cell transplant in the last 6 months
 - Undergoing active chemotherapy or radical radiotherapy for lung cancer
 - Undergoing immunotherapy or antibody treatments for cancer
 - People having other targeted cancer treatments which can affect the immune system, such as protein kinase inhibitors or PARP inhibitors

- People with rare diseases and inborn errors of metabolism that significantly increase the risk of infections (such as SCID, homozygous sickle cell, etc.)

[The NHS](#) is currently recommending a strict isolation period of at least 12 weeks. [The CDC](#) recommends that vulnerable individuals contact their physicians for isolation guidelines and to make a plan in case they do become infected. It is best to stock up on medications, non-perishable food, and household supplies to prepare for the potentiality of needing to stay in isolation for a prolonged period of time. One may want to consider arranging for food to be delivered to your home by family, friends, or through a service such as [InstaCart](#).

NOTE: Based on current medical research and understanding, there is no evidence that any form of dysautonomia would increase the risk of infections or complications from COVID-19. Some patients with dysautonomia may have one or more of the underlying conditions mentioned above, which could increase their risk. For example, certain types of dysautonomia are more common in the elderly or are caused by diabetes. However, at this time current research indicates that dysautonomia itself is not a risk factor.

As this is a developing situation, new research and information about who is vulnerable to the virus is released frequently. We highly encourage you to discuss your individual risk and necessary precautions with your medical provider.

How to Practice Good Hygiene and Cleanliness

Wash your hands frequently with soap and water for at least 20 seconds. When applicable use hand sanitizer that contains at least 60% alcohol. When coughing or sneezing make sure to cover both your mouth and nose, preferably with a tissue. Do not reuse tissues, even if there is more space. Avoid touching your face, especially your mouth, nose, and eyes. While your pet cannot catch and then infect you with COVID-19, please keep in mind that any germs on your hands transfer to anything you touch, including fur. Your germs then are transferred to the hands of the next person who touches the animal. Therefore, please wash your hands after contact with your pet.

[The National Institute of Health \(NIH\)](#) stated that the virus can survive on copper for up to 4 hours, on cardboard for up to 24 hours, and on plastic and steel for up to 2-3 days. It is recommended that you launder your clothes, towels, and bedsheets frequently. You should also sanitize phones, doorknobs, sink faucets, light switches, countertops, and other frequently touched surfaces with an EPA registered household disinfectant. You can inexpensively mix your own disinfectant by diluting 4 teaspoons of bleach per 1 quart of water. [For your safety, do not mix bleach](#), ammonia, rubbing alcohol, hydrogen peroxide, detergents, acids such as vinegar, or baking soda together [in any combination](#). Please see [this CDC webpage](#) for detailed advice on cleaning and disinfecting.

[World Health Organization \(WHO\)- Advice for the Public](#)
[Center for Disease Control \(CDC\)- How to Protect Yourself](#)

Face Masks and Coverings

[The CDC](#) and [WHO continue to request](#) that individuals do NOT use N95 respirators or surgical masks unless they have a confirmed case of COVID-19, are a caregiver for a confirmed case, or are medical personnel. There continues to be a dire shortage of medical grade masks in many countries, including the United States. Masks need to be reserved for medical personnel, the infected, and caregivers of the infected. If you or your business are in possession of single-use N95 respirators or surgical masks that are not required, please consider donating your masks to your local hospital or health department.

On April 3, 2020 the [CDC updated their recommendations](#) asking for everyone to wear cloth face coverings in all public situations, even if you do not feel sick. We now know that there are many asymptomatic carriers of the virus who are unknowingly infecting those around them because they think of themselves as “safe”. Wearing a cloth face covering helps protect other people in case you are infected. Cloth face coverings should NOT be worn by children under the age of 2, anyone who has trouble breathing, or anyone who is unable to remove the covering unassisted. Remember, cloth face coverings do NOT replace social distancing, which is critically important to stopping the spread of the virus.

The CDC has also published [written instructions](#) on their website for sewing a cloth face mask and a no-sew method for a cloth face covering. The CDC also posted a [YouTube video](#) that demonstrates how to make a no-sew cloth face covering. Please make sure to use cloth that can be laundered, as you must routinely wash your cloth coverings in the laundry or with disinfectant soap.

Social Distancing

[The WHO advises](#) that you maintain a safe distance of at least 6ft or 1m between you and other people, especially if they are coughing or sneezing. When one coughs or sneezes they spray respiratory droplets into the air that may be infected with COVID-19 or other viruses. Maintaining a safe distance helps protect you from potentially inhaling these infected droplets.

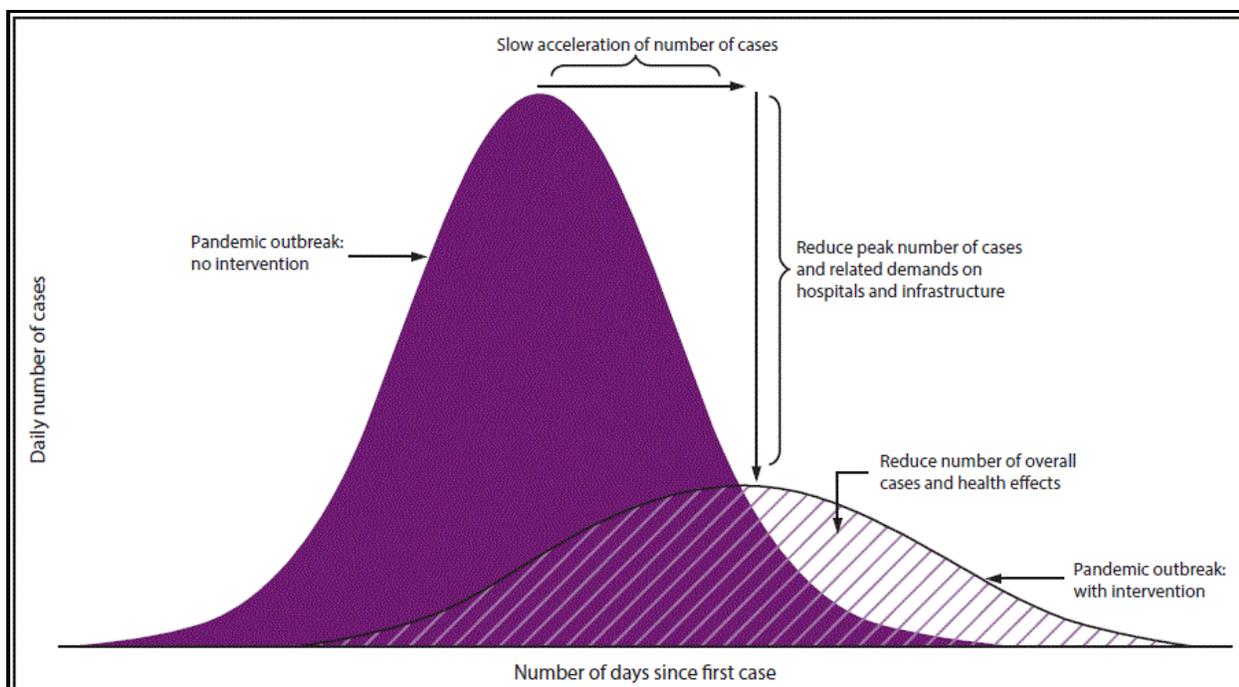
Take extra effort to avoid close contact with those who are sick or showing symptoms, but please keep in mind that it can take up to 14 days after infection for symptoms to appear. Additionally, [testing data from numerous countries](#) and [several recent studies](#) indicate that about 1/3 of COVID-19 patients are asymptomatic or pre-symptomatic. This means that you and anyone you encounter could be infected with COVID-19 and not know it.

Please limit your movement outside home as much as possible. Ask your employer if you can work from home during this time. Consider cancelling/postponing non-essential travel, shopping trips, dining in restaurants or bars, and social visits as much as possible. If you must buy a meal from a restaurant please choose takeout, delivery or a drive-thru. Avoid gatherings of people such as religious services,

concerts, and other events. [The White House has](#) urged citizens to avoid gatherings with more than 10 people, but please be advised that some localities are under strict lockdown and disallow social gatherings. Please check with your local health department for details specific to your community.

Why Practice Social Distancing?

Recently you may have heard the phrase "[flatten the curve](#)". Below you can see a chart [published by the CDC](#) that displays this concept with two exponential curves. The curves are mathematical projections of the potential number of COVID-19 cases in the coming months, which changes depending on our behaviors as a community. Our goal is to flatten the curve, thus decreasing the total number of cases and spreading them out over a longer period of time.



The purple curve shows what could happen if we do not change our behavior and the community continues to be in close contact with one another. At this rate, if the number of new COVID-19 cases in the United States continues to double or triple every few days, then by May there will be [over a 100,000 cases](#). Put simply, if we do not change our behavior then COVID-19 will be able to spread very, very quickly making enormous groups of people sick in a very short period of time. The problem with having many people sick simultaneously is that there is a finite number of medical personnel, hospital beds, respirators, and other resources. If everyone becomes sick at the same time then the healthcare system could become overwhelmed. Possibly not everyone would be able to be treated and more people would suffer, or even die. Sadly, [Italy has endured](#) this worst case scenario.

The good news is that we can slow the spread of COVID-19 by practicing social distancing. Social distancing involves avoiding public places and physical contact with others, thus slowing the transmission

of COVID-19 throughout communities. The flatter, striped curve shows a reduced total number of cases that are spread out over a longer period of time. By spreading out cases over a longer period of time the burden on the healthcare system would be reduced. Hospitals would be less likely to run out of beds, medicine, or medical equipment such as respirators. It is up to every individual to act responsibly in order to protect the population.

[Institute for Health Metrics and Evaluation \(IHME\)- COVID-19 Projections](#)

[Washington Post- How to "flatten the curve"](#)

[Live Science- What is "flattening the curve" and will it work?](#)

Work Disturbances

If you have experienced a layoff or reduction of work hours as a result of COVID-19 please contact your state Employment Commission and ask if you could qualify for unemployment insurance benefits. Due to the circumstances, many states have changed the requirements or waived waiting periods in order to give relief to more people.

Mental Health Resources

This situation can be stress inducing in a variety of ways due to health concerns, financial concerns, social isolation, and intrapersonal concerns. If the situation and social isolation are causing excess stress perhaps you could benefit from mental health support at this time. If you already have a mental health provider, we would suggest contacting them first to ask how they are handling appointments at this time. Many providers are adapting by holding sessions by phone, Skype, Facetime, or other digital means.

If your provider is cancelling sessions or if you do not currently have a provider and would like to seek a digital source of mental health support during this time, please visit our [Mental Health Resources](#) page which we have updated to provide information relevant to COVID-19.

Links to other organizations

[The Ehlers-Danlos Society](#)

[The Mastocytosis Society](#)

[Bobby Jones Chiari and Syringomyelia Foundation](#)

[National Organization for Rare Disorders](#)

[Centers for Disease Control and Prevention \(CDC\)](#)