

The VOICE of FTD

SPRING 2020

Map Your Plan for Coronavirus

Information and resources to support you during the COVID-19 pandemic

The novel coronavirus known as COVID-19 has the world in various stages of turmoil, isolation, uncertainty, and just plain craziness. This is uncharted territory for many and can be scary and overwhelming. The good news is that there are things you can do to protect yourself and your family physically, mentally, and emotionally. Having a plan for dealing with COVID-19 puts you in the driver's seat.

Here at the FTD Disorders Registry we have implemented a plan as Registry business continues. Our team members are taking recommended precautions. We work from home, practice good hygiene, and follow social distancing. We touch base weekly during scheduled video meetings and periodically connect through email, online chat, and other digital apps. We will continue to serve our participants and the FTD community.

Our heartfelt wishes go out to everyone during these unusual times. We encourage you to stay informed, stay connected while following recommended precautions, and be prepared by mapping out your own plan as together we live through this pandemic.

"Information is powerful," stated FTD Disorders Registry Director Dianna Wheaton, Ph.D., CHES. "It is important that the information be reliable and comes from a trustworthy source. This type of information provides guidance and enables people to cope by engaging in tangible actions."

KNOW THE FACTS

Planning starts with knowing what this virus is ... and isn't, how it spreads, and how you can protect yourself, your family, and others.

COVID-19 is a novel (or new) coronavirus that has not been seen in humans before now. There are many types of human coronaviruses. Some are serious, like severe acute respiratory syndrome (SARS), and others cause mild upper-respiratory tract illnesses, like the common cold.

COVID-19 is serious because it is new and because there currently is no vaccine and no specific antiviral medicine to prevent or treat it. However, specific drug treatments and possible vaccines are being tested through clinical trials.

The World Health Organization (WHO) lists the primary symptoms of COVID-19 as fever, tiredness, and a dry cough. However, a person may also have aches and pains, nasal congestion, runny nose, sore throat, or diarrhea. The symptoms are usually mild and begin gradually. Some people become infected but don't develop symptoms. About 80% of infected people recover without needing special treatment.

According to a study led by researchers at Johns Hopkins Bloomberg School of Public Health, the median number of days for symptoms to appear after exposure is 5. The majority of people (97%) will show symptoms

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within 11 Days. A study at the University of Texas at Austin determined that about 10% of people who have the virus never show symptoms.

The U.S. Centers for Disease Control and Prevention (CDC) has confirmed that this new coronavirus primarily spreads from person to person through small droplets from the nose or mouth which are spread when a person with COVID-19 coughs or exhales. Other people can catch COVID-19 if they breathe in the droplets. In addition, after the droplets land on objects and surfaces around the person, others can catch the virus by touching these objects or surfaces, then touching their eyes, nose, or mouth.

This is why it is important to stay more than 6 feet away from other people and practice good hygiene.

PROTECT YOURSELF

The best way to prevent becoming infected is to avoid exposure. Stopping the spread is the reason for the numerous Shelter in Place orders and the recommended social distancing of keeping 6 feet away from others when out in public.

Staying home except to obtain essentials, including food, medicine, and necessary medical treatment greatly reduces your chances of getting sick. If you must go out, cover your nose and mouth and sanitize your hands frequently.

Anthony S. Fauci, M.D., director of the National Institute of Allergy and Infectious Diseases, said that people with serious chronic conditions should think twice about going anywhere, especially crowded places. He advised “not putting yourself in a situation — whatever that might be — that might increase the risk given your situation.”

Additional guidelines from the CDC and WHO to minimize your risk include:

- Washing your hands for 20 seconds.
- Keeping your hands away from the face, especially eyes, nose, and mouth.
- Maintaining a distance of 6 feet from others when



outside your home.

- Coughing or sneezing into your elbow.
- Using disposable tissues and throwing them away immediately.
- Wiping frequently contacted surfaces with an alcohol-based cleanser.
- Avoiding groups and crowded surroundings, including family gatherings and public transportation.

Avoiding others protects you from becoming infected. And if you do get it, distancing protects others, especially before your symptoms appear.

CARE FOR OTHERS

Dementia-related behaviors, increased age, and common health conditions may increase a person’s risk of contracting COVID-19. This virus can present challenges for people with certain health issues, especially respiratory illnesses. This includes persons affected by certain types of frontotemporal degeneration (FTD).

To keep loved ones safe and healthy, caregivers have special challenges. The following section offers information pertaining to specific types of FTD.

PSP

Those with PSP are more vulnerable than the average person to developing pneumonia caused by the coronavirus and are less able to cough up the secretions as needed to allow the pneumonia to resolve itself.


COVID-19 infects the entire respiratory system — not

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just the nasal passages in mild cases (rhinitis, or a “cold,”), the bronchi in moderate cases (bronchitis), and the lungs in severe cases (viral pneumonia). There are many secretions that have to be managed, and people with PSP beyond the initial stages have difficulty with that, Lawrence I. Golbe, M.D., CurePSP’s director of clinical affairs, wrote in a coronavirus advisory.

“PSP impairs the ability to swallow or expectorate secretions, which allows them to drip down the windpipe. This can itself turn a cold into pneumonia,” Dr. Golbe explained. “A second and probably more important problem is that once one does have pneumonia, the vigorous coughing-up of the lung’s secretions, which is essential to recovery, is impaired in PSP. This allows the secretions to fill the spaces in the lungs where air should be flowing, reducing the availability of oxygen to the tissues. A more dangerous result is that the inflamed lung tissue is a good place for bacteria in inhaled air to produce a second pneumonia on top of the first, called a ‘superinfection.’”

This advice applies to any neurological disorder that impairs the ability to manage respiratory secretions, including corticobasal degeneration (CBD) and multiple system atrophy (MSA).

PPA

People living with primary progressive aphasia (PPA) present special challenges, noted Marsel Mesulam, M.D., a member of the Association for Frontotemporal Degeneration’s (AFTD) Medical Advisory Council. Some may not be able to find the words to formulate their questions or express their feelings. Others may have difficulty understanding what they read in newspapers or hear on television. Such communication struggles can cause additional frustration, confusion, and apprehension.

Friends, family members and care partners need to be mindful of these difficulties. Dr. Mesulam offered the following helpful suggestions for caregivers of persons living with PPA:

- ◆ Assist with word selection. Take a proactive role by offering word choices that appear suitable.
- ◆ Go at their pace. Give individuals ample time to express themselves. Creating space for communication at the pace possible for them is crucial.
- ◆ Listen patiently. Even if the correct word cannot be found, the person may be able to convey their thoughts through lengthy circumlocutions.
- ◆ Simplify and repeat. Understanding COVID-19 information is challenging for any of us, but for people with PPA, it will be helpful to review it together, simplify it as much as possible, and repeat the process as often as is reasonable.

“For most people with PPA, telephone conversations are even more difficult than face-to-face communications,” he said. “The isolation mandated by COVID-19 becomes particularly problematic for these individuals because it may not be possible to alleviate it by contact through electronic and social media.”

Dr. Mesulam recommends care partners and family members keep improvising and seeking methods to maintain communication channels open that work for them and their loved one.

GRN MUTATION CARRIERS

While FTD is not generally considered to be an immunocompromised condition, progranulin gene (GRN) mutation carriers may face increased susceptibility to COVID-19, noted Murray Grossman, M.D., C.M., a member of the AFTD Medical Advisory Council. “If we or our loved ones with FTD are 60 or older, we face increased risk for a more severe infection.”

Communication pertaining to COVID-19 may be particularly challenging in a variety of ways. People with FTD may be unable to communicate effectively that they are not feeling well. They may have difficulty remembering to wash their hands or to maintain social distance. They also may have trouble being empathetic or insightful enough to understand how not following

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these practices may pose risks for others.

“All of these factors make it doubly important to engage in good practices to help protect those around us,” Dr. Grossman said. “Your thoughtfulness and vigilance in these challenging times will help protect those with FTD as well as caregivers, families, friends and acquaintances from COVID-19.”

WRITE YOUR PLAN

Whether you live alone or your household encompasses a large family, sit down together while everyone is well and make decisions now to protect others should someone test positive for the virus. This is similar to having a plan for other catastrophic events such as bad weather or a house fire.

Talk with the people who need to be included. Plan ways to care for those who might be at greater risk for serious complications. Discuss what to do if someone in your home tests positive for the virus and what the responsibilities of each person will be.

Designate a room or space in your home to isolate a sick person from the healthy people. Stock it with supplies. This includes separate bedding, eating utensils, medical items including a thermometer, and if possible, a separate bathroom. If you don't have the items and facilities to separate sick people from well, plan for extensive sterilizing.

This part of the plan is to contain the virus and prevent its spread to others. You will need to clean and disinfect areas more thoroughly wearing disposable gloves, using detergent or soap and water, and following up with a disinfectant. If you don't have disinfectant, you can make your own using 4 teaspoons of bleach per quart of water (or 5 tablespoons of bleach per gallon of water).

Consider different scenarios for individual roles and tasks based on if each person becomes ill. Who will prepare meals? Who will tend to the sick person? How will they cover their face when entering the quarantine space? Where will they wash after leaving?

Create an emergency contact list. Ensure your household has a current list of emergency contacts for family, friends, neighbors, health care providers, teachers, employers, the local public health department, and other community resources.

Watch for the symptoms and call your healthcare provider should someone develop a fever, cough, and/or have shortness of breath. Isolate the sick person to protect others in the home.

Get immediate emergency help if someone has trouble breathing, becomes confused, is unable to be awakened, or has bluish lips or face. In each case, **call** the appropriate healthcare provider first and follow their instructions.

Be sure everyone knows the plan. Write it down and tell all where it is.

Finally, practice. Remind everyone of the importance of practicing daily the preventive actions that can help prevent the contracting and spreading of respiratory illnesses.

REDUCE STRESS

Social distancing and sheltering at home should not result in isolation. No matter what your personality style, everyone needs some time alone and time with others.

While social distancing is designed to help ensure physical health and slow the spread of the coronavirus, consider mental and emotional distancing to take care of your overall well-being, recommended Tracy Brower, Ph.D., a sociologist and principal with Steelcase Applied Research + Consulting.

Take breaks from your consumption of coronavirus news and from social media, create free zones and friendly boundaries with others, be grateful and support others, focus on the future and reassure yourself things will return to normal. Until they do, take care of yourself holistically — and take care of others.

Dr. Brower recently offered eight tips to managing

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your mental health during these uncertain times in a [Forbe Business article](#):

1. Take a break from (social) media. Have a quiet period each day where you turn off the news, log off social media, and stop listening to all of the voices talking about COVID-19.
2. Create a physical location in your home that is a “safe zone” where you won’t consume information about the coronavirus.
3. Set boundaries with people to “get together” whether on the phone or for (virtual) coffee but not discuss COVID-19.
4. Be grateful. Gratitude has been repeatedly found to inspire feelings of positivity and mental health. Find something every day for which to be grateful.
5. Support others. Research also shows helping others by supporting community members has significant positive impacts on mental and emotional health. This may be as simple as writing letters — yes, snail mail! — or making phone calls to those who don’t have much social connection.
6. Exercise for the benefit of your body and your mind, whether a walk outside or toe-touches in your living room. Regular movement is good for your overall health.
7. Get outside since being in nature tends to expand perspective. Seek some sunshine and breathe in the fresh air.
8. Seek optimism. Focus on the future by reminding yourself this is an unprecedented period of time, but that things will get back to normal.

The CDC has these additional recommendations:

- Try to eat healthy, well-balanced meals.
- Get plenty of sleep.
- Avoid alcohol and drugs.
- Make time to unwind. Try to do some other activities you enjoy.
- Connect with others. Talk with people you trust about your concerns and how you are feeling.

Taking care of yourself, your friends, and your family can help you cope with stress. Helping others cope with their stress can also make your community stronger.

Reducing stress is important but even more so for caregivers. Disruptions in daily routines, social isolation, and anxiety are all added stressors. As a caregiver, there are steps you can take to help reduce stress and take care of yourselves so that you can continue to provide care to your loved ones.

- **Stay in touch.** Social isolation and social distancing doesn’t mean cutting off contact with others.
- **Be adaptable and positive.** Your attitude influences stress levels for both you and the person you’re caring for. Focus on how to adjust to the situation in a constructive way.
- **Deal with what you can control.** Outside factors like the coronavirus outbreak are out of your control: how you react to them is not.
- **Clear and refresh your mind.** Find something that works for you and do it regularly!
- **Don’t overload on news.** Staying informed is important, but constantly checking news sources and social media can add to stress levels.
- **Share your feelings.** Sometimes just talking about your stress can help relieve it.

Finally, reach out for help when you need it. There are numerous resources available both online and by phone. Continue reading for details.

RESOURCES FOR MORE INFORMATION

There are numerous places to learn more about COVID-19, to stay updated with the latest information, and to seek any support you may need. However, remember that experts say to avoid social media and to not follow any advice for medical treatments that does not come from a reliable source.

Here are some reputable sources for information and help:

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AFTD

The AFTD has a page on their website addressing COVID-19 and FTD. It provides basic information about this virus, how it can affect people with FTD, how you can minimize your risk, and tips for handling situations unique for people with FTD.

AFTD's HelpLine — 866-507-7222 — offers guidance and assistance to have your questions or concerns answered. In addition, you can sign up to receive updates via their newsletter or visit their [Facebook](#) or [Twitter](#) pages.

[AFTD COVID-19 PAGE](#)

CUREPSP

CurePsp has a page on their website with resources for connecting, managing anxiety and stress, maintaining mindfulness and moving, and staying entertained through music and arts.

In addition, CurePSP offers opportunities to connect with others who are facing similar hardships, as well as ways to speak with peer supporters, connect on their SmartPatients forum, attend a tele-conference support group, or watch a Zoom webinar.

[CurePSP COVID-19 PAGE](#)

CDC

The COVID-19 section on the CDC's website provides a vast amount of information, including disease information, prevention, assistance, and frequently asked questions.

The CDC also has a Disaster Distress Helpline — 800-985-5990.

[CDC COVID-19](#)

WHO

The WHO has a dedicated website section listing practical advice to protect yourself, answers questions, provides news and updates for global research, and even has a myth buster section which separates fact from fiction.

[WHO COVID-19](#)

No matter where you live, COVID-19 has upended many facets of life. Even the research community is affected with in-person visits halted for most studies.

But remember, other pandemics have come and gone through the centuries. Tell yourself daily that this will end one day, too. As former British Prime Minister Benjamin Disraeli said more than 150 years ago: "I am prepared for the worst, but hope for the best."

There is hope and help. It is prudent to be wise and plan.

**Join the Registry.
Tell Your Story.
Advance the Science.**

"Together, we can make a difference!"

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