COVID-19 and Epilepsy

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What is the coronavirus and COVID-19?

- The novel coronavirus is a virus that humans had not previously been exposed to.
- Just like the flu, it is spread by droplets in the air when a person with the virus coughs, sneezes or talks. The droplets may also stay on surfaces for a while.
- Some people who are exposed don't get sick.
- If a person gets sick after being exposed to this virus, they can get COVID-19.
- The main symptoms of COVID-19 are cough, fever, pain, and shortness of breath.
- While most people who develop COVID-19 will have only mild to moderate symptoms, some people may need to see a health care provider or be hospitalized.
- A small number of people will get very sick and need breathing help or may even die from complications.

What can people do to limit exposure to the coronavirus?

Follow the advice of the Centers for Disease Control and Prevention (www.cdc.gov) and local authorities to help slow down the spread of COVID-19. Here are important tips for everyone to protect themselves.

- Wash your hands regularly with soap and water for 20 seconds
- Avoid touching your eyes, nose and mouth
- Cover your cough or sneeze with a tissue, then throw the tissue in the trash
- Keep at least 6 feet between you and others
- Avoid close contact with people who are sick
- Consider wearing a mask when you leave the house
- Follow guidelines from your community on when to self-quarantine
- Stay home if you are sick and call your health care provider first if you need an appointment
- Clean and disinfect frequently touched objects and surfaces

Are people with epilepsy at higher risk of developing COVID-19?

Available data suggests that people with epilepsy alone or with seizures as their main symptoms do not have a higher risk of getting COVID-19. Also having epilepsy alone does not does not increase the severity of COVID-19 if they develop it.

- Talk with your health care provider to understand your own risk.
- Continue to follow the treatment plan provided by your healthcare provider.

For people with epilepsy, what factors may increase the risk of serious problems from COVID-19?

Some people with epilepsy, regardless of seizure control, have other health conditions and treatments that may put them at higher risk from COVID-19.

- **Medications:** Some medicines to control seizures also affect the immune system (for example, ACTH, steroids, everolimus, immunotherapies). However, most seizure medicines do not affect the immune system. If you have any questions about the medicines you take, ask your health care provider.
- **Other neurological conditions:** Some people may have other conditions or developmental issues that affect their immunity. People with these condition may be at greater risk of developing more severe symptoms with viral illnesses.
- **Other health conditions:**
  - People who have problems swallowing or frequently inhale food or liquids into their lungs (aspiration) are at higher risk for pneumonia.
  - Problems such as diabetes, heart or lung problems may increase your risk for severe COVID-19.

If you are concerned that you or your loved one may be at increased risk, please speak to your health care provider to see if specific medical precautions are needed. Follow precautions to avoid getting sick too.
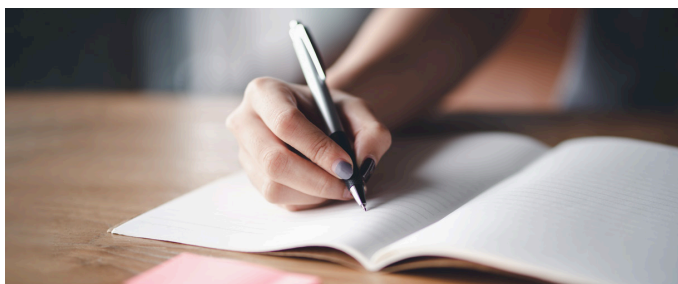
Managing epilepsy in this challenging time

How can I stay on top of managing my seizures?

Follow basic seizure first aid and make sure others around you know how to help when a seizure happens.

- Know the 3 steps to seizure first aid – Stay. Safe. Side.
- Most seizures are not emergencies and can be managed at home with seizure first aid.
- Be extra careful taking your seizure medicine – **don't miss any doses.**
- You may be out of your usual routines. Set up a reminder system that will work for you. Some ideas to consider:
  - Set an alarm on your phone.
  - Use a pill box
  - Use a **text reminder app** or **seizure diary**
  - Use sticky-notes reminders
  - Ask someone to remind you when to take your medication
  - Use a **checklist** to make sure you took them

Keep an adequate supply of seizure medicine available.

The Centers for Medicare and Medicaid Services (CMS) has relaxed rules for people who have Medicare Part D prescription drug plans or Medicare Advantage plans. Some private insurance companies and pharmacy benefit managers are changing their rules too. Some plans may be more flexible– for example, remove prior authorization requirements, waive prescription refill limits, and relax home and mail delivery of prescription medicines.

- Contact your pharmacy first to see if you can get at least **1 month** supply of medicines – make sure this includes seizure medicines taken on a daily basis or used as a rescue medicine.
- Some pharmacies, especially mail-order pharmacies will allow up to **90 day supply** of medicine.
- Call the Epilepsy Foundation's 24/7 Helpline if you are having trouble getting your medicines or need financial help. **English: 1-800-332-1000 and en Espanol: 1-866-748-8008**
- If you are told the supply of your medicine is short, contact your pharmacy. If they are unable to help, let your doctor know as they may need to substitute another medication for a short period.

Make sure you have a seizure action plan and keep it updated.

- Ask your epilepsy team if you should have a rescue medicine to use in case of a change in seizures. Rescue medicines do not take the place of daily seizure medicines. They can be used to help prevent a seizure emergency and prevent the need to go to an emergency room.
- Make sure family, friends and your health care team have a copy.

Stay in touch with your health care team.

Many clinics and offices are cancelling or rescheduling routine appointments. This is being done to limit exposure to others who have acute illnesses like COVID-19 and to free up doctors and nurses to deal with urgent visits. Other clinics and practices may do visits with you by phone or by computer (called telehealth visits).

- Before your visit, call your provider's office to check if the visit is still on and how it will be done.
- Ask what number to call if you need to talk to your epilepsy team. Some hospitals are using nurse triage lines to help answer questions too.

How can I manage my stress and worry?

This is a stressful time for everyone. People may be alone or caring for other people. Routines have changed. Listening to news may be making people more scared of getting sick.

While we can't prevent all stress, look at how you are managing it. Chronic stress can lower one's immunity. This may make you more prone to getting sick. Consider different ways to manage stress.

- Set daily routines – get up and go to bed at regular times, sit down for meals with family or house mates, take walks or get some type of exercise
- Build relaxing activities into your routines – reading, listening to music, drawing or painting – whatever is enjoyable for you.
- If you have a yard, try gardening or outdoor work. Remember to keep distance from your neighbors. Getting fresh air is good for your physical and emotional health.
- Take breaks from news and avoid listening or watching at night if it's making sleep hard.
- Practice mindfulness techniques – this may be meditation, deep breathing, quiet listening, tai chi, yoga or other activities.
- Connect with others – staying connected is probably the most important thing we can do right now. Call family or friends, text message or set up video calls. Do whatever works for you.
- If you normally see a counselor to help with stress, worry or depression, make sure you have a way to keep these connections. Ask if they will do phone or video calls.
- Keep up with healthy habits.

Managing Changes in Seizures

Can seizures increase if a person gets COVID-19?

When a person with epilepsy gets sick with COVID-19 or another illness, especially with a fever, they may see a change or increase in their seizures. The illness is a physical and emotional stressor to the body that could make seizures more likely. Early information from countries where outbreaks have occurred suggests that the risk of more seizures with COVID-19 seems low for most people with epilepsy.

Tips to help control seizures:

- Follow healthy habits – eat and drink as normally as possible and get a good amount of sleep.
- Treat the symptoms of COVID-19.
  - Take over-the-counter medicine to keep a fever down. Initially some concern was raised that ibuprofen could make COVID-19 more severe. There is little data to support this. Acetaminophen (Tylenol) or ibuprofen can be used.
  - Most cold medicines are fine. Avoid cold medicines with pseudoephedrine if possible – this can affect seizures in some people. Talk to your health care provider about what is best to use.
- If you are vomiting or have diarrhea and are unable to keep your medications down, make sure you call your health care provider to ask what you need to do.
- If you or a loved one develop COVID-19 and notice changes in seizures, contact your epilepsy health care provider for advice specific to your situation.

My seizures are worse – what should I do?

Don't go to an emergency room unless it is an emergency. Many times you can be treated at home.

- Call your providers first. Don't just go to their office without an appointment – this could put you or other people at risk for getting the virus.
- Many providers are offering "virtual visits" (called telehealth) by phone or computer. These can be just as useful as an in-person visit.
- Talk to your doctor or nurse about a seizure action plan. If you already have one, update it.
- If needed, your provider may recommend an adjustment in seizure medicine or recommend a rescue medicine to use during periods of increased seizures. If you already have been prescribed a rescue medicine, talk to your pharmacist about an emergency supply.
- However, just like any other time, if you or a loved one have an emergency, such as seizures lasting too long or more seizures than usual, seek emergency help.

When should I go to an emergency room for seizures?

COVID-19 is likely to result in busier emergency rooms. There will be many more patients than the doctors and nurses usually see so expect waits. Also, emergency rooms will have sick people and you can pick up illnesses there! Try to avoid emergency rooms and urgent care clinics as much as you can. This will reduce the risk of you or a loved one contracting COVID–19.

- If you think you need to be seen urgently, try to talk to your doctor's office first if it is safe to do so.

The following are examples of when you may need to go to an emergency room:

- A seizure with loss of consciousness lasting longer than 5 minutes and no home rescue medicine is available.
- A seizure that continues for an additional 5 minutes after rescue medicine has been given.
- Seizures that are occurring back to back without allowing a person to recover between them. Again, if rescue medication is available, give that first and allow 5 minutes for it to work.
- A seizure emergency that can't be treated safely at home – for example a person has seriously injured themselves or is having trouble breathing.
- A seizure where someone has hit their head very hard.

Managing Symptoms of COVID-19

If I (or a loved one in my house) is at risk for developing a serious form of COVID-19, should I take extra precautions?

- Follow the precautions described by CDC.
- Stay home as much as possible – your community may not let you go out, or restrict you to only certain places.
- If another member of your direct family who lives with you becomes ill, consider the following:
  - Can they stay with someone else? If not possible, each person should have their own room, use separate bathrooms, and wash their hands often.
  - Use careful handwashing and clean all surfaces and rooms frequently.
- If you or a loved one with epilepsy works or goes to a day program in your community, talk to a manager about alternatives:
  - Work from home
  - Close the office or agency
  - Attend only small group activities if offered.
  - Participate remotely
- If you or your loved one live in a group setting (group home, assisted living, or other long-term care facility), talk to the administrator and medical staff of the facility. Find out what precautions are being taken. If you have concerns about these, talk to your own health care team to see if any adjustments are needed.
- If you have help come into your home, follow common sense and make sure people helping you are following good health practices. Talk to the agency responsible for the people coming into your home – try to have consistent people to limit the number of people you are exposed to.
  - Have some form of mask and gloves available for home health workers to use if needed.
- Have a back-up plan for help in the home too.

What should I do if I think I have COVID-19?

First call your health provider. The symptoms of COVID-19 are similar to the flu or common cold. The provider will ask you a number of questions to see if you are likely to have COVID-19 or some other illness.

- The most common symptoms of COVID-19 are fever, cough, or difficulty breathing. If these symptoms are mild to moderate, your provider may recommend that you stay home. This means "quarantine" yourself – don't go out in public or have others come into your home.
- Symptoms can often be treated at home. Ask your provider,
  - Which over-the-counter medicines are safe to use with your seizures?

- What to do if symptoms change or don't get better?
  - Should you be tested for the flu and COVID-19? If the symptoms are mild, they may not do tests right away.
- If symptoms don't get better or you develop shortness of breath or pain, call your doctor.
- If you live with other people, keep away from them. Wear a mask when around other people in the house. Stay in one room, use your own bathroom, and don't share food or utensils. If you share bathrooms, clean after each person's use.
- If you help care for another person or your family, separate yourself physically in the home away from them. Enlist help from others, family, friends, home care agencies or volunteers who can safely care for others you are responsible for caring.
- If seizures increase, call your epilepsy team or neurologist.

We are Here for You

The Epilepsy Foundation and our nationwide network of local organizations are here to help before and after an emergency.

- Call our **24/7 Helpline** for personalized help and resources, find a local Epilepsy Foundation near you, or search our online database for local resources.

  Call 1-800-332-1000 (English) or 866-748-8008 (en Espanol)
- Learn about epilepsy, treatments and caring for yourself and others for you. Connect with others too at www.epilepsy.com
- Visit www.advocacy.epilepsy.com to learn about federal and state policies and laws that may affect your family.

More Resources

- U.S. Centers for Disease Control and Prevention (CDC): www.cdc.gov
- FDA Resources for Patients: www.fda.gov/patients/coronavirus-disease-2019-covid-19-resources-patients
- Patient Advocate Foundation COVID Care Resource Center: www.patientadvocate.org/covidcare
- American Red Cross: www.redcross.org or call 1-800-RED-CROSS
- www.211.org or call 211 from any phone: local resources
- American Epilepsy Society – www.aesnet.org/about_aes/position_statements/covid-19/patients-families