

Epi (CARE

EUROPEAN REFERENCE NETWORKS FOR RARE, LOW PREVALENCE AND COMPLEX DISEASES

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COVID-19

General advice for persons with epilepsy March 30th 2020 Authors: ERN EpiCARE STEERING COMMITTEE

COVID-19/ GENERAL ADVICE FOR PERSONS WITH EPILEPSY

Never discontinue your antiepileptic medication without medical advice from an adult or child neurologist.

Families and patients should avoid presenting at emergency departments and understand that it may be advisable to postpone all hospital visits, unless absolutely necessary, in order to avoid the risk of people becoming infected. If needed call your family doctor or your epilepsy specialist.

Individuals with epilepsy are not more likely to be infected by the virus.

Currently there is no information that people with epilepsy are more severely affected by COVID-19 than people without health conditions. We have no reason to believe that this could be the case.

We have no evidence that coronavirus can trigger seizures in people with epilepsy.

Some very rare forms of epilepsy (Rasmussen; Electrical Status Epilepticus in Sleep) sometimes treated with medicines that also affect their immune system (for example, ACTH, steroids, immunotherapies) may be at greater risk of developing more severe symptoms with viral illnesses. However, these medicines should NOT be interrupted. A rigorous respect of extra measures to social distancing should be sufficient. If you are concerned call your epilepsy specialist.

For some epilepsy syndromes, where seizures may be provoked by fever, the usual precautions should be taken. Paracetamol can be used – there have been suggestions that ibuprofen may facilitate or aggravate the coronavirus infection, and although there is no clear evidence that this is true, it may be prudent to avoid it until further data is available.

People with epilepsy may have other medical problems that could place them at higher risk of developing more severe symptoms with COVID-19. For example, people with restricted mobility, respiratory conditions (including asthma), diabetes mellitus, hypertension, severe heart disease, impaired immune function due to underlying conditions or drug treatment, obesity and older age.

If you experience a prolonged seizure at home, do not hesitate using emergency rescue medication earlier than usual (for example, after 2-3 minutes of an ongoing tonic-clonic seizure).

If seizure presentation changes think making a home video and request a **teleconsultation**.

An EEG should be performed only if considered indispensable by an epilepsy specialist.

Keep a list of antiepileptic medications you take (including details on daily dose and administration modalities). Systematically share this list with the doctor you may consult. Some antivirals and other medicines may interact with an antiepileptic drug, reducing its effectiveness or resulting in adverse effects.

Currently there is no evidence of shortage of supply of antiepileptic medication over and above country specific issues. However, because of current confinement policies, ensure a **regular supply of medication**, do not wait the last day to visit your pharmacist. **Stockpiling of medication should be discouraged**.

More than ever, please ensure that you take your antiseizure medicines regularly and that you do not miss doses. Also ensure that you keep a healthy lifestyle and avoid factors, such as lack of sleep, that may facilitate the occurrence, or recurrence, of seizures.

If you were in the process of weaning an ongoing antiepileptic medication you should postpone it and seek for advice from a specialist in epilepsy. If you are undergoing changes in your medication, please also consult your epilepsy doctor to determine whether such changes should be reversed or postponed. These recommendations are intended to minimize the risk of your seizures getting worse at a time when the availability of medical services may be curtailed.

If you are living alone make sure having a regular contact with a family member, a friend or even better with a neighbor several times a day.

If you suffer from associated anxiety and/or depression, call if needed your epilepsy specialist and/or neuropsychologist or psychiatrist.

Children receiving methylphenidate for an Attention Deficit – Hyperactivity Disorder (ADHD) should not interrupt treatment during confinement.

Contact: If you are looking for **emergency medical advice** and you want us to transfer your request to a member of the European Reference Network for Rare and Complex Epilepsies EpiCARE in your country you can write to our **Epilepsy Nurse Coordinator**: <u>ghe.epicare.coordination@chu-lyon.fr</u>. Provide the age of the patient and not more than 5-10 lines summarizing the emergency issue you are facing. Considering the priorities all medical teams are facing during the ongoing pandemic crisis only medical emergencies will be treated.

Please refer to official sources when looking for information.

Do not believe and avoid diffusing fake information.

- WHO: https://www.who.int/emergencies/diseases/novel-coronavirus-2019
- ILAE: https://www.ilae.org/patient-care/covid-19-and-epilepsy/covid-19-and-epilepsy
- EPNS: <u>https://www.epns.info/covid-19-and-neurological-disorders/</u>
- NHS: www.nhs.uk/conditions/coronavirus-covid-19/
- LICE: https://www.lice.it/pdf/vademecum_coronavirus.pdf
- LFCE: https://www.epilepsie-info.fr

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Co-funded by the European Union