

TIPS FOR PATIENTS AND PARENTS

1. Search for reliable information

Patients and parents are recommended to search for reliable sites, such as the

World Health Organization

(<https://www.who.int/emergencies/diseases/novel-coronavirus-2019>)

and the **Centre for Disease Control**

(<https://www.cdc.gov/coronavirus/2019-nCoV/index.html>) for COVID-19.

If patients and parents want more information about epilepsy, they can search on the International League against Epilepsy webpage (<https://www.ilae.org/patient-care/covid-19-and-epilepsy>)

Sources:

<https://www.who.int/emergencies/diseases/novel-coronavirus-2019>

<https://www.who.int/emergencies/diseases/novel-coronavirus-2019>

<https://www.ilae.org/patient-care/covid-19-and-epilepsy>

2. News: remember to take a break from news

During contact isolation, news consumption has increased with advances in technology (e.g., mobile devices) and the rise of social media.

Media use generates the world's perceptions as threatening, and repeated exposure to news stories involving violence may result in post-traumatic stress symptoms, anxiety, and depression.

Persons with generalized anxiety disorders are more likely to monitor developments. News of COVID-19 represents a source of uncertainty since new

measures are adopted and modified daily. Persons with psychiatric disorders who do not tolerate ambiguity evaluate the uncertainty of the pandemic as threatening even when adverse outcomes are unlikely, leaving them at risk for the development or maintenance of anxiety and depression.

It is recommended that the amount of exposure to news and media should be restricted for adults, adolescents, and children with epilepsy and psychiatric disorders.

3. Social distancing is not social isolation: Connect

To the combination of a lack of regular social activities and staying at home for a longer time can impact on emotional well-being. Research has also shown that sudden outbreak can worsen the mental health conditions of those with pre-existing mental health illness.

However, social distancing differs from social isolation. The quarantine demands lead to an important decrease in physical contact. However, **this is a moment to connect with families and friends.**

To **maintain a healthy relationship, get in touch with friends and family members on a regular interval** using social media and **start thinking positively.**

If you feel you are becoming too anxious about coronavirus:

- try to share the fear with others (family or friends)
- try to increase self-awareness by getting adequate sleep, exercising regularly and employing different relaxation techniques.

- if necessary, in this era of technology, healthcare services can provide online psychological support services

Sources:

Ho CS, Chee CY, Ho RC (2020) Mental health strategies to combat the psychological impact of COVID-19 beyond paranoia and panic. Ann Acad Med Singap 49(1):1

Kecmanovic J (2020) 7 science-based strategies to cope with coronavirus anxiety. The Conversation. <http://theconversation.com/7-science-based-strategies-to-cope-with-coronavirus-anxiety-133207>. Cited 30 Mar 2020

Centre for Disease Control: <https://www.cdc.gov/coronavirus/2019-ncov/index.html>

4. Build a routine for you and your family

The pandemic has led to a disruption in our daily routine. **The faster you build a new routine, the better!**

Having a regular routine is important for physical and mental wellbeing and can help to ease the disturbance caused by the loss of the usual daily structures of work and school.

Finding activities are likely to help you and your child's mental health.

It is helpful to create a new daily timetable of activities.

5. Sleep

Trying to maintain normal sleep/wake cycles will help preserve good mental health, and significant increased use of stimulants, such as **coffee, or sedatives, such as alcohol, should be avoided**

Sleep and health lifestyle behaviors, including diet, influence our mental health and stress response. Sleep and family can be important resilience-related factors.

There are special considerations regarding persons with epilepsy and psychiatric disorders. Patients with psychiatric disorders may have difficulties to sleep because of stress (e.g., anxiety or mood disorder) or lack of routine and therapies (e.g., autism spectrum disorder, ID). It may cause a vicious cycle: sleep deprivation may lead to seizure worsening that increases stress.

If environmental changes do not help, look for online support with our physician or a neurologist specialized in sleep disorders.

Source: Holmes EA, O'Connor RC, Perry VH, et al. Multidisciplinary research priorities for the COVID-19 pandemic: a call for action for mental health science. *Lancet Psychiatry*. 2020;7(6):547-560. doi:10.1016/S2215-0366(20)30168-1

6. Minimizing Treatment Barriers

During the pandemic, critical support and therapies are often reduced or canceled. Many people with mental disorders have some form of regular psychotherapy and psychiatric treatment. Therefore, the lack of access to health services can be particularly detrimental. The severity and outcome of mental disorders could worsen because of delays in prompt diagnosis and treatment.

Telemedicine is an option to maintain treatment during the pandemic. Existing tools can be adapted, and confidentiality and data protection must be assured. User-friendly systems that can be used by all age groups, regardless of abilities, are recommended. In general, children and adolescents are familiar and do not have difficulties with the programs used. It is also relevant to provide a safe and confidential space at home. There is strong evidence that online-delivered psychotherapeutic care for children and adolescents is feasible and effective. It is recognised as a primary source of standard care in times of restricted physical contact.

Medication - Parents and patients in need of ongoing medication should be advised to stock a certain amount in case of a disruption in supply.

Furthermore, doctors could issue extra prescriptions to ensure that patients have sufficient medication during phase two of the pandemic.

Caution: This is not the best moment to transfer the responsibility of medication to your child or adolescent.

Parents must monitor medication use in children at risk for self-harm.

7. Dealing with suicidal feelings

For some people the pressures during the epidemic may build up so that they experience feelings about harming themselves. If you have these feelings please talk to someone either friends family, professionals you work with or charities who may provide help lines to call. (<https://www.mind.org.uk/information-support/helping-someone-else/supporting-someone-who-feels-suicidal/how-to-help/>;
<https://www.samaritans.org/?nation=wales>)

Sources:

European Society for Child Adolescent Psychiatry. Dealing with children and adolescent mental health during the Coronavirus pandemic. [https:// www.escap.eu/index/coronavirus-and-mental-health/dealing-with-child ren-and-adoelscent-mental-health-during-the-coronavirus-pandemic](https://www.escap.eu/index/coronavirus-and-mental-health/dealing-with-child-ren-and-adoelscent-mental-health-during-the-coronavirus-pandemic). 2020.

American Academy of Child and Adolescent Psychiatry. Coronavirus/ COVID-19 Resource Library. <https://www.aacap.org/coronavirus>. 2020.

Diamond R, Willan J. Achieving Good Mental Health during COVID-19 Social Isolation. *Br J Psychiatry*. 2020 May 4 : 1–2.

Kar SK, Arafat SMY, Kabir R, Sharma P, Saxena SK. Coping with Mental Health Challenges During COVID-19. *Coronavirus Disease 2019 (COVID-19) 2020* : 199–213. Published online 2020 Apr 30. doi: 10.1007/978-981-15-4814-7_16

TIPS FOR PARENTS

Supporting a child with epilepsy and a psychiatric disorder can be a struggle for parents. The Psychiatry Commission of the International League recommends:

1. Seek for personal support if you need

During the pandemic, parents can be overwhelmed. They may have to provide homeschooling while still working at home. In addition, they are supposed to maintain a healthy environment, convey precise messages to their children and adolescents and provide financial support for the family.

Parents may need support and they should not be ashamed to search for it. Again, online therapy or counselling helps.

Remember that parents are doing the best that they can! However, no one has gone through a pandemic before. Acknowledging your fears and personal stress is a good way to recognise that we are all vulnerable. We are reinventing ourselves and finding a different lifestyle. It is not easy, but we may end up learning during the process.

2, Talk to children about the COVID-19 (if they wish to)

Children need to receive clear and concise information from reliable sources. Children with epilepsy may have questions about the pandemic like any other child. COVID-19 issues be hard to explain and difficult to understand for a young child. However, most children can easily understand that most children and adolescents have a milder form of the disease with symptoms and signs that resemble the flu.

Parents have the chance to show that adolescents can have accurate data from **credible sources** instead of those obtained from social media. **Parents can print**

material that they can read, if necessary. By doing it, parents create a chance to discuss "fake news."

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- **Clear and honest answers.** Create an open and supportive environment where children know they can ask questions when this information is requested. The answers must be honest with concepts that are easy-to-understand and follow the child's developmental level.
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- **Reassurance:** Parents must be prepared to repeat and explain more than once the same information. Curves and terms such as exponential growths are hard to understand, and children may seek reassurance.
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- "I understand how hard it is..." or "I understand your feeling about it..."
Acknowledgment and validation about thoughts, feelings, and reactions precede any explanations and create the bridge for a consistent relationship. If the child or adolescent feels that their feelings or thoughts are minimized or ridiculed, they may not seek help.
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- **Don't force the subject for children.** Although parents are frequently receiving and seeking information about COVID-19, children may not share the same interest. Sometimes, children wish to be children, and after the first moment of adjustment, they may not want to talk about it
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- **Monitor the youth's information and effect.** For adolescents with access to social media, it is of interest to discuss their knowledge, monitor their sources, and show the precise way to obtain information. Since adolescents, especially with chronic diseases, are at high risk for internalizing symptoms, parents should address the two issues that are intolerable to people of any age: uncertainty and isolation.
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3, Behavior and attitudes speak louder than words

Children and adolescents learn from watching their parents' behavior. Parents' response to news about the coronavirus outbreak or conversations between adults will determine their attitude and level of stress.

If parents and siblings are overwhelmed by the COVID-19 crisis, their emotional stress may aggravate the child's depression, anxiety, or other psychiatric disorder. A brief inquiry by the clinician about each family member's mental health status would enable a discussion about the importance for family members to seek treatment if needed.

Parents may want to know how to help their child cope with this new world of COVID- 19.

Tips:

The child or adolescent should be reminded that **the current situation is temporary** and that they will be able to resume the enjoyable parts of their life.

Efforts should be made to **spend more time than usual**, if possible, with the child and to encourage thinking about or contacting relatives. These are stressful times, but the family connection is a soothing comfort for children.

Source: Wagner KD. J Clin Psychiatry 2020 Apr 21;81(3):20ed13394. doi: 10.4088/JCP.20ed13394)

4. News for children

For children and adolescents, news, even of political events may be interpreted as threatening and result in distress. The **American Academy of Child and Adolescent Psychiatry recommends** that children unable to understand some complex messages conveyed by media should **avoid frightening images**. The repetition of such scenes can be disturbing and confusing.

Remember that parents and teachers may follow the news and the daily updates with interest and attention, **children must not**. Therefore, parents must be careful with information about the country, politics, or the current situation of COVID-19 in the world.

5. Children may personalize situations!

Children personalize situations. They worry about their safety and the safety of immediate family members. For children with epilepsy and psychiatric disorders, they may also express concerns about their seizure control during quarantine or if they have COVID-19. Besides, children and youths may worry about their care in case of parents' sickness. Children and adolescents with internalizing symptoms need information and reassurance, as previously stated.

The ILAE website (www.ILAE.org) provides information about seizures and epilepsy during COVID-19 for families, patients, clinicians, and researchers.

In summary, it is essential to remember that:

1. A small group of children gets worse with fever. In general, children and adolescents with epilepsy do not present seizure worsening during infection.
2. It is vital to maintain healthy habits during the pandemic. Some patients may present seizure aggravation with sleep deprivation and stress.
3. Parents must be realistic. As their child or adolescent has epilepsy, parents must show a clear plan about the children's treatment plan, in case they need isolation.
4. Lots of people are helping the people affected by the coronavirus outbreak. There are people to help.