

Surviving COVID 19 from a psychological perspective: Advice for people with epilepsy and their families

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On behalf of the IBE

Introduction

In January 2020 the World Health Organization (WHO) declared the outbreak in China of a new coronavirus disease, Covid-19, to be a Public Health Emergency of International Concern. WHO stated that there was a high risk of COVID-19 spreading to other countries around the world. In March 2020, WHO made the assessment that COVID-19 could be characterized as a pandemic.

Our responses to the Covid-19 pandemic at an individual level will vary based on our experience of coping with health issues and other life problems generally. For some individuals and their families, they may develop stress due to the uncertainty of the pandemic and the risk of being infected. Stress reactions can include low or depressed mood, anxiety, frustration, irritability, anger and social isolation.

This article addresses the concerns that people with epilepsy may have about the condition and what practical solutions may be taken to help them cope from a physical, psychological and cognitive perspective.

Concerns of People with Epilepsy

In preparing this article we asked our colleagues, Dr Sallie Baxendale and Professor Martin Bunnage, both of whom are providing telephone, skype or zoom services for their clients, to identify the concerns that have been expressed to them. These are the concerns their clients have identified:

- Do I belong to a vulnerable group and because of my epilepsy am I at greater risk than others without epilepsy?
- Will a change in routine have an impact on my seizures?
- How do I cope with the impact of the lockdown?
- Will the supply of my antiepileptic medication be affected?
- What will happen about my regular hospital appointments?
- Will my treatment be affected e.g. will I have to wait long for surgery?
- Can I still contact my neurologist or epilepsy specialist nurse or therapist [neuropsychologist/ counsellor]?

Many of the questions are directed at the medical aspect of epilepsy and the IBE and ILAE will have posted information in relation to them. There will be a number of support organisations

in each country that also may assist in helping answer specific questions or at least put people in touch with medical staff who might be able to answer them.

The impact of the Covid-19 will vary from one person to another. Surprising for some there has been an improvement in the control of seizures, while for others the anxiety of Covid-19 might result in a deterioration. If there is a negative change then that is a reason for seeking medical advice. The Covid-19 pandemic also means that there may be delays in elective treatment e.g. surgery or attending routine appointments - and this can be frustrating and worrying. We know that some epilepsy centres will have made arrangements to support people who attend their hospital.

In thinking about the lockdown, we have created the following diagram for people with epilepsy adapted from work done by Dr Lesly Murphy. The diagram highlights the challenges that people with epilepsy might have to face [right side] and the possible solutions [left side].

It is important to recognise that Covid 19 is an unusual and threatening situation and one where there is a great deal of uncertainty. It is perhaps surprising that most people will feel out of control. So how can we deal with not feeling in control. In this article we want to provide the challenges of the lock down and provide ideas that might help with managing the situation.

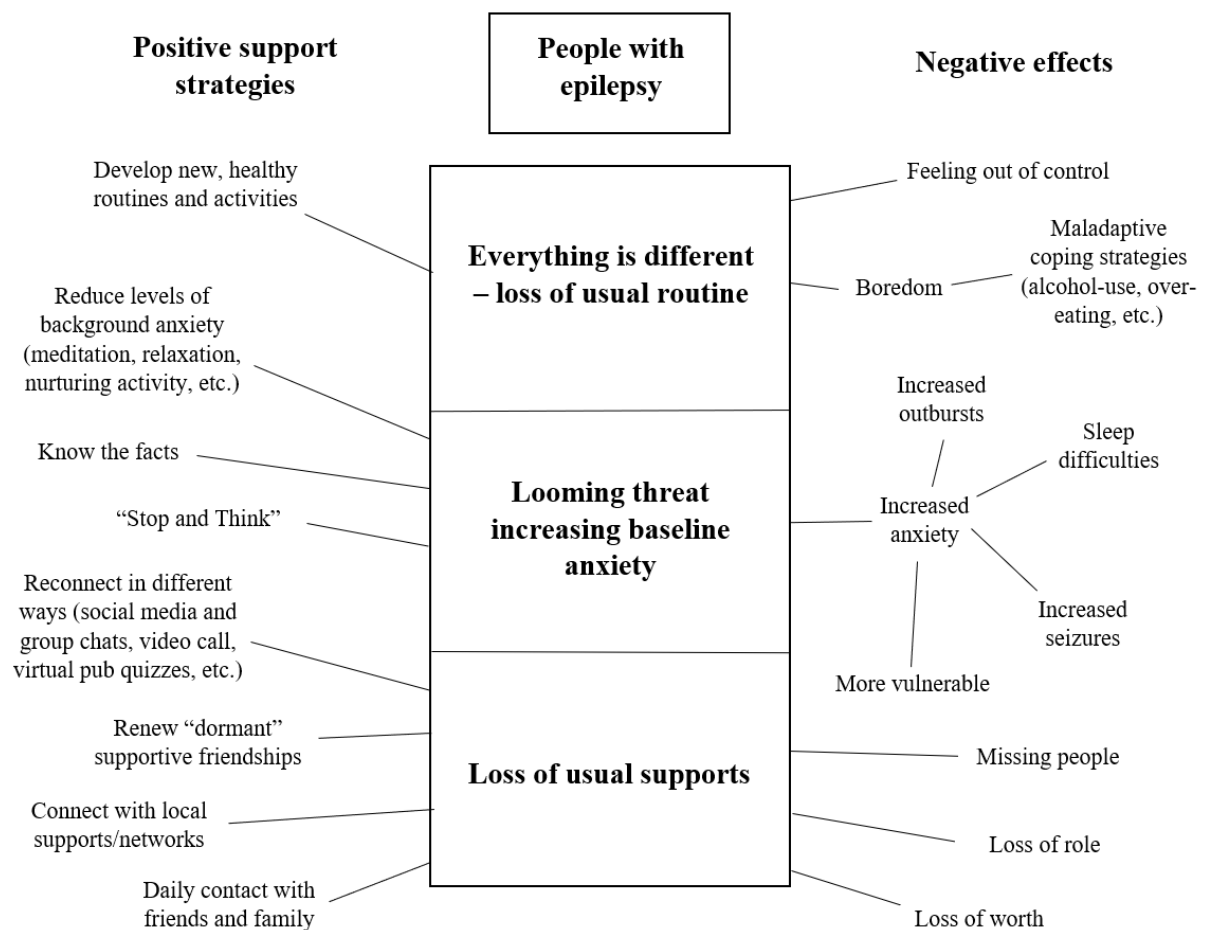


Diagram Barriers and Strategies for managing Covid-19 Pandemic

Feeling out of control

Some individuals may well feel overwhelmed by their thoughts and fears about contracting the virus or managing the lockdown. It is important to recognise that we cannot control what happens in the pandemic nor can we control the decisions made by others e.g. restricting movements, social distancing, closing down workplaces and cessation of employment. However, we can try and control some aspects of our everyday life.

Suggestions

- Share your thoughts and fears with others including a family member or friend
- If worry plays on your mind and bothers you or interferes with your day, then ask yourself can you control what you are worrying about? If you can, then spend 10-15-minutes thinking of solutions and plan what you can do now.
- If you are worrying about a problem that you can't control, then try postponing the worry or distract yourself from the worrying thoughts. Or remind yourself that your worry is just a thought and that thoughts come and go.
- Try to pay attention to the present and not think too far ahead at this time.
- Find pleasure in the smaller things that we usually take for granted or don't have time to do, like cutting the grass, cooking and sitting out feeling the warmth of the sun.

Education and Knowledge

The WHO suggests that you should minimize watching, reading or listening to news about COVID-19 that causes you to feel anxious or distressed;

Suggestions

- Seek information only from trusted sources and mainly so that you can take practical steps to prepare your plans and protect yourself and loved ones.
- Seek information updates at specific times during the day, not more than once or twice daily. The sudden and near-constant stream of news reports about an outbreak can cause anyone to feel worried.
- Get the facts; not rumours and misinformation. Gather information at regular intervals from local health authority platforms in order to help you distinguish facts from rumours. Facts can help to minimize fears.

The IBE and ILAE websites have provided helpful information how your epilepsy may or may not be affected by COVID 19.

Communication

Communication is central to our ability to stay emotionally well. Although contact is challenged by the current circumstances it is more important to maintain than ever.

Suggestions

- Keep in regular contact with loved ones (e.g. via telephone, e-mail, social media or video conference).
- Share your worries over your concerns with people you trust.
- There are a number of helplines and online forums for people with epilepsy.

Taking care of yourself

In times of uncertainty it is important to look after yourself physically, psychologically and emotionally.

Suggestions

- Be prepared and know in advance where and how to get practical help if needed, like calling a taxi, having food delivered and requesting medical care.
- Make sure you have up to two weeks of all your regular medicines.
- Learn simple daily physical exercises to perform at home, in quarantine or isolation so you can maintain mobility and reduce boredom.
- If you have a garden, spend some time there or alternatively go for a walk.
- Make sure you get enough sleep and try to maintain a regular sleeping pattern.
- It is important to keep your mind active as well as your body. This could mean learning a new hobby, improving existing skills, making a playlist etc.

Maintaining relationships during Covid -19

We don't normally spend so much time at home with our partners and family. We all need to develop a new normal for all being at home together.

Suggestions

- If you or your partner are working from home, talk about how this is working for you and them. You may need to get creative with the space if you are both working from home. Take turns to share the most comfortable and quiet spot and share childcare so that you can both get some work done.
- Try to deal with bickering by talking about the shared frustration with this virus and realise that we are all in this together.
- Big and difficult decisions or conversations may need to be put on hold while you handle the current situation, and if these issues have been the cause of arguments with your partner, then call a truce during this time to make living under one roof more bearable.

- Treat each other with kindness and compassion especially as the outside world can feel quite threatening.
- If you are getting frustrated or upset, count to 10, take some deep breaths, walk away and calm yourself down.
- If you're getting frustrated with others in the house, it might be an idea to share how you're feeling by getting in touch with a trusted friend.
- Remember that children will see and learn from how you deal with conflict, so keep this in mind when you are all under one roof together.

Routine and Structure

Getting into a good routine and controlling your worry, as well as looking after yourself generally, will help with your epilepsy. Regular exercising, cleaning, daily chores, singing, painting or other activities are all important.

Suggestions

- Keep regular routines and schedules as much as possible or help create new ones for the new environment.
- Write a timetable for the forthcoming week.
- Set yourself goals and build a weekly plan to meet those goals.
- Keep the same routine with taking your medication and with your sleep.
- Use the memory support techniques and reminders that work for you, with regard to taking your antiepileptic medication and for general day to day things. That might be a dosette box for your medication or a Smartphone App to remind you when to take your medication.
- For memory generally, keeping a diary, using lists, notes, a white board with reminders and generally having a routine can all help.

Final Tips

- [1] Set a routine. If you are spending more time at home it is important to continue with a regular routine.
- [2] Stay mentally and physically active.
- [3] Notice worry triggers and try to limit the time that you are exposed to them each day.
- [4] Rely on reputable news sources.
- [5] Stay connected to others.