

## Keeping safe with COVID19 and epilepsy

Corona virus, also known as COVID19, is currently affecting all aspects of our lives. We are facing an unprecedented time of uncertainty, restrictions and limited services. If you or someone you care for has epilepsy, this may be a significant concern for you, leaving you with many questions. This factsheet aims to provide you with practical information and support in these difficult times. If you need to talk, contact our helpline on 0808 800 2200. We are here for you.

### **Beware information overload and misinformation**

We are being bombarded with information on social media and TV, which can make it difficult to separate fact from fiction. Too much information at once may cause anxiety and affect your mental health.

You need to give yourself a break from the daily onslaught of news for your emotional and mental wellbeing. Choose when you want to read or hear media information, maybe once or twice a day, to keep up to date. Restrict yourself to information from reliable sources only such as NHS Inform in Scotland, and the Scottish Government and UK websites:

<https://www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-covid-19#overview>

<https://www.gov.scot/coronavirus-covid-19/>

<https://www.gov.uk/guidance/coronavirus-covid-19-information-for-the-public>

We are not going to repeat general advice on how you can keep safe and protect yourself against the virus. There's plenty of information already out there. This factsheet is about issues and questions specific to epilepsy.

## Are you more at risk of catching COVID19 if you have epilepsy?

There is no evidence that you are more likely to catch COVID19 because you have epilepsy unless you have other underlying health conditions which may compromise your immune system. **Epilepsy does not affect your immune system.** General agreement among medical professionals is that a person on anti-epileptic drugs is **not** at an increased risk of contracting COVID19 or any other infections.

Anti-epileptic drugs are **not** considered immunosuppressants. There has been a lot of information on social media suggesting otherwise, but there is no robust evidence for this.

Most standard anti-epileptic drugs which are commonly and widely prescribed are not classified as immunosuppressant drugs. There is no strong and reliable evidence that they weaken a person's immune system; clinical studies on different drugs have shown conflicting and inconsistent results. It's also worth noting that results of tests on animals and in the laboratories do not necessarily translate to any problems in humans.

If you remain concerned about this, contact your epilepsy specialist nurse by telephone who can give you more specific information on the anti-epileptic drug(s) you take. Never stop taking your anti-epileptic drugs unless advised by your specialist, as suddenly stopping your medication can result in a serious seizure, potentially putting your life at risk.

## Can COVID19 increase seizures?

Having epilepsy does not automatically mean you will experience severe symptoms if you catch COVID19. Remember, in many cases, symptoms are mild, or you may not even know you have it.

If you are showing symptoms of COVID19 or suspect you may have it, you need to be mindful of certain things which may put you at an increased risk of seizures. Typical symptoms include a fever and coughing. Depending on the severity of the symptoms, this can, of course, also affect your sleep. It is well known that running a temperature, feeling unwell, pain, and lack of sleep can be a trigger for seizures for some people.

Because serious symptoms of COVID19 can increase the risk of seizures, many people feel those with epilepsy should be put in the 'high risk' category, which means you are considered more vulnerable. However, government guidelines have not included people with epilepsy.

It's also worth noting that anxiety and stress can put you at an increased risk of seizures. There is more on how to deal with anxiety and stress below to help you stay as seizure free as possible.

## **Keep taking your medication**

Keep taking your medication exactly as prescribed even if you feel unwell. This is the most important measure you can take to protect yourself against increased seizures. Keep an eye on your seizure activity, and if you find seizures are on the increase, get in touch with your epilepsy specialist nurse.

If you have or suspect you have COVID19 and your symptoms are more serious, seek medical advice by phoning NHS24 on 111. Mention you have epilepsy and the effect this may be having if you experience increased seizures. If necessary, you will then be referred to one of the COVID19 Assessment Centres in Scotland for further advice and support.

Also be aware that your routine might be different at the moment, whether you are self-isolating, working from home or generally are unable to do the things that give your day a structure, such as going to the gym or out for a walk. You may stay up later and sleep longer in the morning, which could have a knock-on effect on your

medication timings. For example, if you always take your medication after breakfast, this could mean you end up taking your medication much later than your usual time or even forget to take it. This will put you at an increased risk of a serious breakthrough seizure. Set an alarm reminder on your phone so you remember to take your medication.

## How to contact your specialist nurse during this time

As you may know, many non-urgent medical appointments have been postponed or are now conducted via the telephone. You can still seek medical advice if you are concerned about increased seizures or anything else to do with your epilepsy. In the first instance you should phone your specialist nurse's usual number and listen carefully to the recorded message. This will tell you how to get in touch with your epilepsy specialist service, and how long it may take for someone to phone you back. In some instances, you may be redirected to another number. This varies from area to area.

## Availability of epilepsy drugs

Contrary to what you may have heard or read, there is still a good supply of anti-epileptic drugs coming into the UK. Please don't believe everything you read on social media.

In fact, drug companies have been asked by the UK Department of Health and Social Care, and the Scottish Government, to continue to stockpile medication. This was an established protocol in preparation for Brexit, and warehouses are already full of additional drug supplies. Should there be a disruption in supply chains because of COVID19, these stockpiles will tide over drug companies, which will minimise the risk of drug shortages.

Please note that drug shortages can happen for a number of general reasons.

This could, for example, be due to difficulties with the manufacturing process, or because one of the ingredients is currently not available. So, if your drugs are currently unavailable this may not have anything to do with COVID19.

If you have difficulty getting your specific anti-epileptic drugs, contact your GP or epilepsys specialist nurse by telephone.

## Repeat prescriptions

Try not to wait until you are due to run out of your medication. If your GP allows, request a repeat prescription in good time, but be mindful that you should only order when you need your drugs as stockpiling can indeed cause drug shortages. If you order a week ahead, this should give your pharmacist plenty of time to order or source your prescribed medication. Most GP practices allow you to request a repeat prescription online or via the phone, so there is no need to hand this in personally.

If you are in isolation because of symptoms or health concerns, you may be unable to pick up your prescription in person and take it to the chemist. Most GP practices have systems in place to avoid patients coming to the surgery. Prescriptions can be sent directly to a nominated chemist. Find out from your surgery what arrangements they have put in place for repeat prescriptions.

Some chemists can deliver directly to your home, but a home delivery service may not always be possible due to the high volume of requests. Ask a friend or family member if they can help and drop your medication on your doorstep.

## What if you need more help?

There are many local groups offering to help. You can usually get in touch with them via Facebook by searching for your area and keywords such as 'Corona virus, COVID19, COVID Mutual Aid' etc.

In the first instance, however, contact your local social work department who will advise on an approved agency, church group or charity group who can offer further support such as shopping for you or picking up prescriptions and medicine. If you don't know your local social work department's number, contact us on our helpline 0808 800 2200.

While most individuals offering to help are totally genuine, be mindful of scams which have sadly emerged since the COVID19 crisis. Exercise a sense of caution when approaching and accepting help from someone you don't know.

## Dealing with anxiety and stress

Right now, everyone is worried and stressed. We are all mourning the loss of our freedom, liberties and are struggling with our vulnerability. Stress and anxiety on its own can be a seizure trigger, but it can also affect our sleep. Lack of sleep or increased tiredness is another potential seizure trigger for those with epilepsy. It's therefore important that you use whatever tools you have to get on top of your anxiety.

While current restrictions make it difficult to resort to usual coping mechanisms like meeting up with friends or going on a walk, there is still a lot you can do to help yourself in these strange times.

Stay connected with friends and family and use some of the many video chat platforms such as Skype, WhatsApp or Zoom. Seeing someone makes you feel more connected. People with epilepsy are no strangers to loneliness and anxiety but having restricted access to your usual ways of coping can increase anxiety.

Have a look at **Anxiety UK**'s website <https://www.anxietyuk.org.uk/> which is full of useful resources and practical tips on dealing with anxiety, and offering mindfulness, breathing and grounding exercises. They have a helpline 03444 775 774 or a text service 07537 416905.

**Breathing Space in Scotland** can also help if thoughts and feelings become overwhelming. They literally offer you some breathing space; someone to talk to in the evening and during the night. You can contact them on 0800 83 85 87' between Monday and Thursday, 6pm to 2am, and Friday 6am to Monday 6am.

If certain aspects of your epilepsy and access to services make you anxious, please contact us on **our helpline 0808 800 2200**. There have been so many rumours and misinformation on social media, we can often allay your fears and concerns by providing you with the facts. We can also signpost you into other services or find out information on your behalf. Our teams are constantly in touch with medical staff and Scottish government sources to get you the most up-to-date and factually correct information. So, before you worry about something you've heard, pick up the phone and talk to us.

## How to stay healthy in general

There are three key areas you should focus on to keep yourself as healthy as possible and your immune system in top condition: stress, sleep and diet. Paying attention to these three areas may also have a positive impact on your seizure control.

We've already covered **stress and anxiety** above. This is a really important area to be mindful of as stress can also negatively impact on your body's ability to fight off any infections.

The second important area to focus on is **sleep**. We know that tiredness and lack of sleep can be a trigger for seizures. Incidentally, the need to sleep can also be a response to extreme anxiety, trauma or grief. In a way, we are all mourning the loss of our liberties and many of us have been moving through the classic stages of grief, such as denial, anger and hopefully a level of acceptance of the status quo for the time being. Grief can be very physical, and the need to sleep is often a key response of your body to cope. If you feel more tired than normal, this could be the

reason. Allow your body to respond to this and get as much rest and sleep as you can.

Generally, stick to a good sleep routine. Avoid stimulating drinks containing caffeine from late afternoon onwards. Consider switching to herbal teas if you like them. Switch off any devices that emit blue light one hour before bedtime if you can. At the very least switch to night mode which reduces the blue light. Blue light can interfere with the production of melatonin, a hormone important for good sleep. Wind down gently towards the end of the day, listen to some music, read a book or have a shower. If there is no shower, it would be advisable to only take a bath if someone else is physically present in the bathroom at all times. If unsure, please seek advice from a specialist health service. Small steps can make a big difference to the quality of your sleep, and stress levels.

And finally, make sure you eat a **healthy and varied diet**. Our body needs plenty of fruit and vegetables for good immune function. Cut down on refined sugars, including biscuits, chocolate and pastries. We know that sugar can suppress the function of your immune system. Also stay well hydrated, preferably with water. A healthy diet is also important for seizure control.

Doing all of this gives you the best possible chance to stay seizure free and fight off any infections.

## Exercising

Exercising remains important. It potentially helps with seizure control, counters stress and anxiety and helps boost your immune system.

While there are many restrictions at the moment to stop you from doing your usual exercise routines, you will still find plenty of opportunities to do something to keep your body and mind as fit and healthy as possible.

This could be a home-based workout or joining one of the many live workout streams that currently are on offer for free. Alternatively, you could do more gentle exercises such as yoga. During lockdown, you are allowed one form of exercise outside, so you can still go out to your local park, go for a run or a cycle, as long as you stay local and observe social distancing rules, staying two metres from anyone coughing. Make the most of what you've got on your doorstep.

Even gardening, if you have a garden, is a form of exercise, it gives you fresh air and a sense of purpose, which can be good for body and soul.

## Contact us

If there is anything we can do to help, we are here for you. We know that loneliness can be a big issue for people with epilepsy in general, but particularly now.

We have launched a “check-in” service during the COVID19 restrictions. If you feel isolated or have increased anxiety register with our Helpline and we will check-in regularly to see how you're coping.

You are not forgotten. You are not alone. Reach out to us, whether this is by social media, email or our helpline **0808 800 2200**.