

Waiting times after the pandemic

One of the long-term legacies of the pandemic that we are all having to live with, is increased waiting times for medical appointments, including those for epilepsy. And this can cause anxiety.

It is hard to predict when waiting times will return to their pre-pandemic levels and, as in so many aspects of daily life, we are having to live with the new normality and find ways to cope.

Peer support on social media

The important thing to remember is that you are not alone, even though it may feel like it at times. We live in a digital world and there are many information resources that you can access online (we have some examples on page 2), as well as peer support.

One of the real benefits of social media is that, night or day, you can go online and engage with other people affected by epilepsy who may be going through the same experience as yourself.

Social media is not a place for seeking medical advice – this should always be from your doctor – but Facebook, Twitter, and Instagram are good platforms for talking and exchanging ideas.

If you're looking for information, then always choose a reliable site. Epilepsy Society's website, has a wealth of useful information (see some of our shortcuts to popular topics on the next page).

Visit epilepsysociety.org.uk or nhs.uk

Technology offers plenty of opportunities for connecting with friends and family online but, not everyone is confident with using Facetime, Teams, Zoom or any of the other platforms that have become part of our lives.

If you are struggling with technology, you could ask for help from a friend, relative, or neighbour. Digital Unite also offers some useful how-to guides that could help you to get connected. It covers everything from email, Facebook, and Twitter to Netflix and online shopping.

Visit digitalunite.com/technology-guides

Calling our Helpline

Of course, not everyone is online. Which is where our Helpline comes in. Every weekday from 9am – 4pm and until 7.30pm on Wednesdays, you can pick up the phone and speak to one of our Helpline operators. Each of them has an in-depth knowledge of epilepsy, and understands the challenges of living with the condition.

The team is also very good at listening and providing emotional support which can be vital for people affected by epilepsy. Time constraints within the NHS mean that, at the best of times, neurology appointments provide little opportunity to really talk about how epilepsy makes you feel.

Contacting a healthcare professional

Even if you are having to wait for an appointment to see your GP, whether face to face or by video or phone call, you may be able to seek support and advice through the GP's online service. Check at the surgery where you are registered to find out whether they have an online service that you could access. This is useful for booking and changing appointments, ordering repeat prescriptions, and getting online advice.

If you feel your epilepsy has changed or, for example, your seizures have become more frequent or severe, make sure you let your surgery or epilepsy clinic know. They may be able to prioritise you.

Your local pharmacist can also be a good person to ask if you have questions about your medication or over-the-counter medications.

From time to time, people experience problems in getting their prescription. This is often because of local supply issues as opposed to shortages.

One of the most useful measures you can take to help you get your medicine as prescribed, is to make sure your pharmacy gets your prescription in good time – up to seven days before you actually need the medication. That way, if the pharmacy does not have your drugs in stock, it gives the pharmacist time to order stock from suppliers or to ring other pharmacies or suppliers, to access your medication elsewhere.

If you are experiencing problems getting your medication, you, or your pharmacist, can call the manufacturer for your particular medicine.

Following the pandemic, many people are facing long waits in between health appointments. Our Clinical Director, Dr Fergus Rugg-Gunn provides practical advice for looking after yourself while you wait.

Epilepsy Society Helpline
01494 601400
helpline@epilepsysociety.org.uk
Confidential, national call rate.
Information and emotional support.

You will find the number on the patient information leaflet that comes with your medication. If you continue to have problems, call our Helpline (details on page 1).

Taking care of yourself

We are living in uncertain times and this, in itself, can cause anxiety and stress, both of which can trigger seizures for some people with epilepsy. This is why it is vital to keep your body and mind as healthy as possible.

- Make sure you are eating regular, nutritious meals and drink plenty of water to keep hydrated.
- Try to get the amount of sleep you know you need.
- Take regular exercise where possible, even if this is only a walk around your garden or around the block.
- Try to get as much sunlight as possible. Even if you are unable to go out, try to sit by a window or on your doorstep. Make sure you ventilate your home so that fresh air is circulating.
- Watching the television can be relaxing but it can also be stressful. If, for example, some news stories cause you to feel worried or anxious, be prepared to give yourself a break.
- Keep in contact with friends and relatives. Call or join them on a video call.
- If you find yourself feeling anxious, take a look at some of our tips for dealing with this. epilepsysociety.org.uk/living-epilepsy/wellbeing/anxiety

Be prepared for your doctor's appointment

Make sure you are ready for your doctor's appointment.

- Keep a list of the issues or problems that you most want to discuss. This is particularly important if you are having to wait for your appointment.
- Keep a record of your seizures, their frequency, and severity. If possible, ask a friend or loved one to film you if they witness you having a seizure. This can provide important information for your doctor in understanding more about your particular seizure types. [Visit epilepsysociety.org.uk/seizure-diaries](https://epilepsysociety.org.uk/seizure-diaries)
- Keep a note of any issues that you want to discuss. This could include side effects of medication such as irritability, tiredness, and lack of concentration.
- If you are experiencing memory issues in everyday life, make a note to tell your doctor. They may be able to refer you to a clinical psychologist who will be able to assess your memory function and suggest strategies to overcome any problems.

Every effort is made to ensure that all information is correct at the time of printing. Please note that information is intended for a UK audience. This information is not a substitute for advice from your own doctors. Epilepsy Society is not responsible for any actions taken as a result of using this information.

- You may be looking forward to a change in lifestyle which is important to discuss with your doctor. Perhaps you are looking forward to starting university. Or, if you are a woman and are thinking of starting a family, it is essential you talk to your neurologist about planning your epilepsy treatment for your pregnancy, and when your baby arrives.
- Some women feel that their seizures are worse around the time of their monthly period; others find that the menopause or hormone replacement therapy can affect their seizure patterns. These are important to note, ready to share with your doctor.
- Many people experience anxiety and depression at some point in their lives and it can be very common among people with epilepsy. You may like to discuss ways of coping with these feelings.
- SUDEP, or sudden unexpected death in epilepsy, affects a very small number of people with epilepsy, around 1 in 1,000. But it is good to discuss your individual risk with your doctor so that, together, you can make sure you reduce that risk.

Shortcuts to epilepsy information

At Epilepsy Society we have a wealth of information, but here are some of our most popular pages. You can find information about epilepsy at

epilepsysociety.org.uk
epilepsysociety.org.uk/wellbeing
epilepsysociety.org.uk/women-and-epilepsy
epilepsysociety.org.uk/seizure-diaries
epilepsysociety.org.uk/university-and-epilepsy
nhs.uk/conditions/epilepsy

Social media

Join the online conversation. Follow us at:

facebook.com/EpilepsySociety
twitter.com/EpilepsySociety
instagram.com/EpilepsySociety

For a printed copy of this information contact our helpline.

Epilepsy Society
Chesham Lane,
Chalfont St Peter,
Buckinghamshire
SL9 0RJ

   @epilepsysociety

**epilepsy
society**