



## CROYDON EPILEPSY SOCIETY

### Winter 2021/22 NEWSLETTER

We hope that our members had a Happy Christmas & New Year.

Since our Autumn Newsletter we have seen the emergence of **Omicron**, the Covid variant from South Africa.

We hope our members have been keeping well and have managed to get the booster jab.

The booster jab is available to all those over 18 if you have had a 2nd dose of the COVID19 vaccine at least 3 months ago.

Restrictions around COVID 19 which had gradually become more relaxed are now increasing again with shoppers being asked to wear masks again in shops and other public places such as cinemas and theatres.

Many places are asking for proof that those people entering their venue have had the necessary jabs. Passes can be downloaded from the NHS website using your phone. <https://www.nhs.uk/conditions/coronavirus-covid-19/covid-pass/>

If you do have symptoms please make sure that you have a lateral flow test and isolate if the test is positive. Packs can be picked up at chemists. It is also advisable to have a PCR test if you continue to have symptoms even though your original test was negative. These tests can normally be requested online and sent in the post to you. If these are not available due to over demand redo the lateral flow test. I have been fortunate not to have had the virus but I know a lot of people who have and have been told by them that on the first day of symptoms the lateral flow was negative but a few days later it was positive. The isolation period has been reduced from 10 to 7 days.

<https://www.nhs.uk/conditions/coronavirus-covid-19/testing/get-tested-for-coronavirus/>

There have been a couple of reports in the news media regarding epilepsy during the last few months.

#### **New NHS Epilepsy Drug**

In November there was news of a new drug called **cenobamate** that can halve or even banish seizures will be given the green light on the NHS. Around 17,000 epilepsy patients could benefit from the new tablet, which experts say will soon be approved by the National Institute for Health and Care Excellence, the NHS drug

spending watchdog. Doctors have hailed the pill as the biggest breakthrough in epilepsy treatment in a decade.

It is estimated that a third of epilepsy patients do not respond to drugs, with some having complex surgery to remove the part of the brain affected. The last big advance in treatment was the launch in the UK a decade ago of Keppra, an anticonvulsant.

It is unclear exactly how it works but it is thought to dampen abnormal electrical energy in the brain. Please refer to your consultant for further details.

NHS.

<https://www.dailymail.co.uk/health/article-10224731/NHS-set-green-light-remarkable-new-epilepsy-drug.html>

## Women's Health

The second report was in December regarding the claim that the NHS "has been neglecting women's health for decades" after a major government review was concluded. Ministers promised to address "decades of gender health inequality" under a Women's Health Strategy to be published in the Spring. A consultation involving 1000,000 British women found eight in ten believe they are not properly listened to by doctors, nurses and healthcare staff.

<https://www.bmj.com/content/375/bmj.n3142.full>

At every stage of life, from puberty through to fertility, menopause and old age, women feel their suffering is ignored. Mention was made of an enquiry last year by Baroness Cumberlege that a large number of women and children were "catastrophically" harmed by three avoidable health scandals one of which was use of **sodium valproate** in epilepsy treatment by pregnant women. Please refer to our Autumn 2020 newsletter for more details.

<https://www.epilepsysociety.org.uk/sodium-valproate>

## Disability Employment Gap

Challenges with finding work and holding down a job are a huge concern for people with epilepsy especially when the job market is unstable due to the effects of COVID. The disability employment gap has remained at 30% since 2013, meaning that for every three non-disabled people in employment, only two disabled people are in work. This has not changed in 8 years. Research from the Office of National Statistics has found that employment rates for people with epilepsy have fallen from around four in 10 (42%) in 2008 to three in 10 (34%) in 2021. It was also reported that people with epilepsy who are in work earn on average 11.8% less than non-disabled people. One major obstacle is that the support the government offers to disabled people when it comes to work is often found by people with epilepsy to not be fit for purpose.

It is difficult to know what to say, what the law says employers should do and what you can ask for. To support people with epilepsy Epilepsy Action has created the Employer Toolkit. <https://employers.epilepsy.org.uk/>

There is also more information for those with epilepsy looking for work. Some of the concerns include asking for reasonable adjustments and disclosing your condition.

<https://www.epilepsy.org.uk/info/employment>

## COVID19 Update

The Croydon Clocktower is no longer providing a **lateral flow test centre**.  
<https://new.croydon.gov.uk/coronavirus-information-and-service-updates/test-and-trace-keeping-croydon-safe/keeping-croydon-safe/rapid-lateral-flow-testing>

There is more information about epilepsy and COVID-19 on the Epilepsy Action website at [epilepsy.org.uk/COVID](https://epilepsy.org.uk/COVID)

Visit [www.gov.uk/coronavirus](https://www.gov.uk/coronavirus) and <https://new.croydon.gov.uk/coronavirus-information-and-service-updates> for the latest government guidance and local information  
<https://www.covid19.nhs.uk/>

### If you need urgent support

If you are living on your own and are still unable to get out to buy food and other essentials like medications please contact local help agencies such as Help the Aged or your local council. See below for Croydon Council details.

The council continues to have a dedicated helpline for residents who need urgent help as a result of COVID-19. Call: 020 8604 7787 – open Monday to Friday, 9am to 4pm. <https://www.croydon.gov.uk/public/coronavirus-covid-19-message-us>

Other information can be found on-line:

<https://www.epilepsy.org.uk/info/daily-life/safety/coronavirus-covid-19>

### Useful Information:

#### **Croydon Health Services Neurology Department:**

**If you are a local support group requesting more information on epilepsy** and for a speaker to come to your group to talk about epilepsy and the support available to those who may have epilepsy or be a carer for someone who has the condition - please email for general enquiries [ch-trspecialistmedicine1@nhs.net](mailto:ch-trspecialistmedicine1@nhs.net).

**There is an Epilepsy Nurse Hotline/Advice telephone number which is open to GP's and patients (who are already known to the Epilepsy Service).** If you are registered with a Croydon GP and under the care of a Croydon Neurologist and feel this service would benefit you please discuss with your GP who would be able to provide you with the telephone number.

**The Croydon Carers Support Centre drop in**, in George Street, Croydon is now back open Monday to Friday, 10am-1pm for drop-in advice and information. You can also call our helpline on 020 8649 9339, option 1 or email [enquiries@carersinfo.org.uk](mailto:enquiries@carersinfo.org.uk).

<https://www.whitgiftfoundation.co.uk/content/carers-support-centre>

**Croydon Age UK** offer a range of practical home services for everyone living in the local area, especially those in later life. Please contact them on 0208 683 7120, or email [homeservices@ageukcroydon.org.uk](mailto:homeservices@ageukcroydon.org.uk), [www.ageukcroydon.org.uk](http://www.ageukcroydon.org.uk)

There is also a Helpline no 0208 686 0066 for general enquiries.

## Croydon Epilepsy Society Contact Details

**Please contact us by phone or email.** Please leave a message on our mobile no or text us and we will get back to you asap.

**Further information can be provided by the following national support groups if you need urgent support:**

Epilepsy Action [www.epilepsy.org.uk](http://www.epilepsy.org.uk) Helpline 0808 800 5050  
Epilepsy Society [www.epilepsysociety.org.uk](http://www.epilepsysociety.org.uk) Helpline 01494 60140

Address: 64 Newlands Woods, Bardolph Avenue, Croydon CRO 9JR.  
Mobile No: 07926372711

Email Address: [croydonepilepsy@gmail.com](mailto:croydonepilepsy@gmail.com)  
Visit our Facebook Page: [www.facebook.com/croydonepilepsysociety](http://www.facebook.com/croydonepilepsysociety)  
Web Site: [www.croydonepilepsysociety.org](http://www.croydonepilepsysociety.org)  
Twitter: Follow us @croydonepilepsy ( <https://twitter.com/croydonepilepsy> )

### Elected Members

#### President

Professor F M C Besag, FRCP, FRCPsych, FRCPCH.

#### Vice - Presidents

Yvonne Green

#### Honorary Vice - Presidents

Dr P B C Fenwick  
Mrs Rosemary Aselford  
Mrs Rita Richmond

#### Committee Members

Mr Marco Valencia Chairman  
Ms Dawn Gibbons Honorary Secretary  
Mr Richard Ruffell Honorary Treasurer

***Don't Hesitate get your booster jab Now!***

***Take care and keep safe!***

