

# EPILEPSY AND COVID-19 ONE YEAR ON

An update report on the impact of COVID-19 on people with epilepsy in Scotland, twelve months into the pandemic

# COVID-19 AND EPILEPSY SURVEY



During the first COVID-19 lockdown in April 2020, we launched a survey to find out how the pandemic was affecting people with epilepsy. We used the results to help shape our response to the pandemic through services and information. We also shared the results with MSPs and other key decision makers to ensure people with epilepsy were considered in policy development.

This year, we relaunched our online survey, seeking to understand how COVID-19 continues to affect people with epilepsy in Scotland.

The survey followed a similar structure, with questions adapted to respond to the current nature of the pandemic.

The anonymised survey was shared with the epilepsy community through Epilepsy Scotland's main social media channels and with a collection of our service users. Collecting both quantitative and qualitative data, we received 70 responses. This report has been informed by these 70 responses.

## EPILEPSY SCOTLAND

Epilepsy is the most common chronic neurological condition in the world. It is a condition which affects 1 in 97 people in Scotland, roughly 55,000 people.

Epilepsy Scotland is Scotland's largest epilepsy charity. We aim to ensure the voices of those with epilepsy and those who care for them are heard. We do this by promoting information across the country to dispel myths and stigma and offer bespoke epilepsy services.

We also influence public policy to make sure the interests of people living with epilepsy and their carers are represented.

# STATISTICAL OVERVIEW



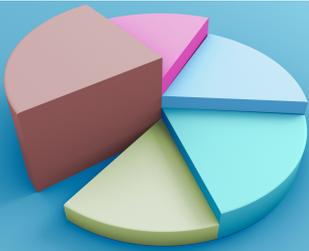
**80%** said COVID-19 has impacted their mental health and wellbeing

**57%** said the pandemic has affected their epilepsy

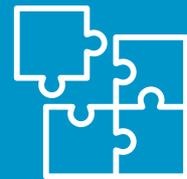
**44%** said their seizure activity increased during the pandemic

**44%** said they have had specialist appointments cancelled

**21%** said they have had support services stopped or cancelled



## MAIN THEMES



- Seizure control
- Mental health
- Access to specialist knowledge and treatment
- Vaccines
- The role of Epilepsy Scotland

This report explores the five main themes which emerged from the survey before comparing the results with that of our last survey.

# SEIZURE CONTROL



For many people with epilepsy, seizure triggers can include stress, tiredness, and high temperatures. These triggers all have the potential to be impacted by COVID-19.

Participants commented on their stress and anxiety surrounding contracting COVID-19, the side effects of the vaccines, and the restrictions of the pandemic, noting that these factors have affected their seizure control.

Some commented on their experience of contracting COVID-19, and how this has, and continues to, affect their seizures.

*"I have had Covid and now have long Covid which is having a big impact on my seizures. It feels scary as nobody understands what it is and how it can affect epilepsy. I feel a bit isolated with having long Covid and epilepsy."*

However, some did say they have become more resilient and better prepared as time has went on.

*"I was very anxious during the 1st lockdown as seizures began again after 5 months clear. Became unpredictable but have recently settled down and I felt more prepared for the second lockdown."*



*"The situation has affected me massively, having had very controlled seizures for 10 plus years, to this year having two massive seizures. This not only affects me but my job, my colleagues and my partner."*

# MENTAL HEALTH



"Worrying about having a seizure outside is always tucked away at the back of my mind but because of the stress and anxiety my seizures are worsening. It's right at the forefront so I'm tending to stay in completely unless I have my husband with me."

80% of survey respondents feel the COVID-19 pandemic has had an impact on their mental health and wellbeing, with respondents pointing to additional stress, worry and frustration about the pandemic and their epilepsy.

When compared to the first lockdown in March 2020, over half of respondents felt more anxious, stressed and depressed this year. Additionally, over 40% felt more isolated now than they did during the first lockdown.

"While I have a better understanding of what is going on and I am better prepared, it's made me so much more stressed, which has had a negative impact on my epilepsy."

There was a general anxiety in many responses about the restrictions of the pandemic lifting.

"Shielding has been hard, very very hard, but now the country is unlocking, the anxiety surrounding it is even bigger."



# ACCESS TO SPECIALIST KNOWLEDGE AND TREATMENT

Over the past year, 44% of respondents have had their specialist appointments cancelled, despite many noting their increased need for specialist support during the pandemic.

*"I think that more of us are feeling somewhat abandoned by the NHS. It's understandable during a pandemic but no less harder to deal with."*

Over half of respondents had not attended any virtual clinical services. Of the 47% who had, some commented on the convenience of virtual appointments, but noted they preferred video to phone. The majority said virtual appointments were not as effective as face-to-face consultations.

*"I have had appointments on the phone with my consultant. I feel they are hurried. Much prefer face to face. I had a video call with another medical professional. That felt much more 'normal'. I prefer video to voice."*



*"Covid/long covid is causing people quite a lot of neurological symptoms and having epilepsy on top of that is confusing and frightening. My seizures have changed and got worse and I have developed new neurological symptoms too... I can't get a quick appointment with my neurologist or even just my GP."*

# COVID-19 VACCINES



*"I'd rather have covid than my seizures return, it took too long to get under control and I'm too nervous to go back to square one."*

The British Medical Journal revealed people with epilepsy are at an increased risk of hospital admission and death as a result of COVID-19. It was therefore welcome news that people with epilepsy were included as a priority group to receive the vaccinations.

91% of respondents have already been, or wish to be, vaccinated against COVID-19. However, respondents flagged their concerns about the vaccines, with uncertainties about how the side effects would impact their epilepsy.

*"I was worried about the vaccine but sought advice from my specialist nurse"*

The Association of British Neurologists advised the vaccines are safe for those with neurological conditions. Some respondents suggested they felt like the possible side effects to the vaccines (e.g. fever and tiredness) may have had an impact on their seizure control.

*"My son had his vaccine and was initially okay but about 12 hours later he developed side effects which caused his temp to spike and increased seizure activity."*

9% of respondents stated they did not want to receive their COVID-19 vaccine.



# EPILEPSY SCOTLAND'S ROLE

Our initial survey asked what information people wanted and needed from Epilepsy Scotland. We acted on the following suggestions:

- More specific information on COVID-19 and epilepsy
- How the benefits system has changed and how to access support - we offered free benefit checks
- More information on medication shortages - we liaised with pharmaceutical companies
- Many said epilepsy was not viewed as high risk by the government - we engaged with the Scottish Government to ensure epilepsy was considered in all relevant policy updates.

This time, we asked the same question. Respondents were satisfied, with many noting they would get in touch if they had queries.

Some suggested we provide more information on topics including new medications, services, and policy changes. There were also calls for more information surrounding COVID-19, particularly the side effects of the vaccines and advice on dealing COVID-19 infection and epilepsy.



*"I receive a lot of good and valuable information that I save for when I may need it - I get this by following the [Epilepsy Scotland] Facebook page. I know I can contact if I need any further assistance so I am happy with what is already available."*

# COVID-19 A YEAR ON...



Comparing the results of our 2020 survey with this year's, we can learn how the experiences of people with epilepsy have changed.

*33% of respondents believe they now have a better understanding of what is going on compared to the initial COVID-19 lockdown.*

*29% of respondents believed they are now better prepared to deal with the pandemic.*



**In 2020, COVID-19 had affected 44% of respondents' epilepsy. In 2021, this rose to 57%.**



**In 2020, 40% of respondents said their seizures had increased during the pandemic. In 2021, this rose to 44%.**



**In 2020, 36% of respondents had their specialist appointments cancelled. In 2021, this rose to 44%.**

These statistics highlight the critical importance of prioritising people epilepsy in all stages of recovery. It is vital that the 55,000 people living with epilepsy in Scotland are considered in the remobilisation of the NHS.

# EPILEPSY SCOTLAND'S SERVICES

*We adapted to meet the changing needs of people with epilepsy throughout the pandemic*



## Helpline

We offer information and support through our helpline and social media. To support those feeling isolated during the pandemic we also launched a new check-in service.

## Communications

We provide accurate and helpful information, keeping our social media followers well informed about epilepsy and the pandemic.

## Wellbeing

We rapidly adapted and expanded our mental health support over the phone and digitally. We are now working with five times as many people from outside our Glasgow base as we were before the pandemic.

## Youth Services

We continue to offer fun and inclusive group activities and one-to-one support online.

## Training

We created online resources and have continued to provide high quality and engaging epilepsy training.

## Welfare Rights

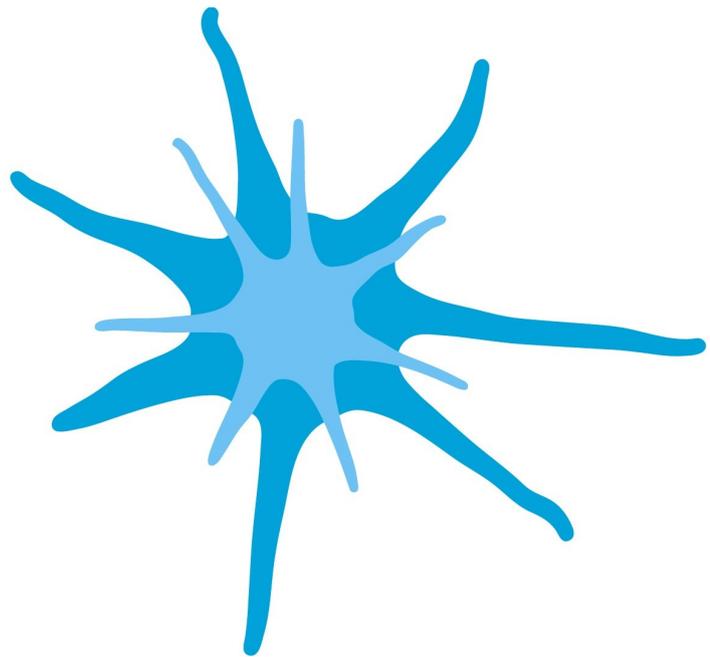
We offered free benefit checks, helping people navigate the claims process and are supporting clients through virtual appeals and tribunals.

## Policy

We monitor emerging policy and share the experiences of people with epilepsy to lobby for better support for people affected by the condition.

## Fundraising

We used new and innovative ways to fundraise during the pandemic and continue to be inspired by the generosity and imagination of our community fundraisers!



## get in touch

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