



SEPTEMBER 2020

# **EPILEPSY AND THE COVID-19 PANDEMIC IN BRITISH COLUMBIA SURVEY RESULTS**

**PREPARED BY:**

BC Epilepsy Society



# ABOUT OUR SURVEY:

In addition to its respiratory symptoms, the COVID-19 Pandemic has had a tremendous psychosocial impact.

Research has shown that people living with epilepsy are more likely to have issues relating to mental health and well-being than the general population.

In response to this, the BC Epilepsy Society and the I AM A VOICE for Epilepsy Awareness™ campaign have come up with a survey to determine the impact of the COVID-19 pandemic on people living with epilepsy in British Columbia, including on their seizures, seizure frequency and/or severity, daily life, etc.

The results from this survey will contribute to a better understanding of the possible consequences of the COVID-19 Pandemic on people living with epilepsy in British Columbia.



## WHAT IS EPILEPSY?

Epilepsy is a medical condition that causes recurring seizures.

A seizure is the sudden, brief and temporary disturbance of electrical activity in the brain.

It has been found that 1 in 12 people will experience a seizure during their lifetime and that 1 in 100 people will develop epilepsy during their lifetime.

Epilepsy affects approximately 1% of the population, with over 65 million people living with epilepsy worldwide; over 3.2 million people living with epilepsy in the United States; over 380,000 people living with epilepsy in Canada; and over 50,000 people living with epilepsy in British Columbia.

## WHAT IS COVID-19?

COVID-19 is the disease caused by the most recently discovered coronavirus, which are part of a large family of viruses that may cause illness in animals and humans.

In December 2019, the first outbreak of the COVID-19 virus was reported in Wuhan, China.

In March 2020, the World Health Organization (WHO) declared COVID-19 as a global pandemic.

## THE RELATIONSHIP BETWEEN COVID-19 AND EPILEPSY

While having epilepsy does not present an increased risk of COVID-19, some of the symptoms associated with COVID-19, such as high fever, cough and difficulty breathing, may put people with epilepsy at an increased risk of seizures.

This may be due to the fact that illness and fever and lack of sleep (as coughing and/or difficulty breathing may keep people up at night) may be a seizure trigger in some people living with epilepsy.



**77%**

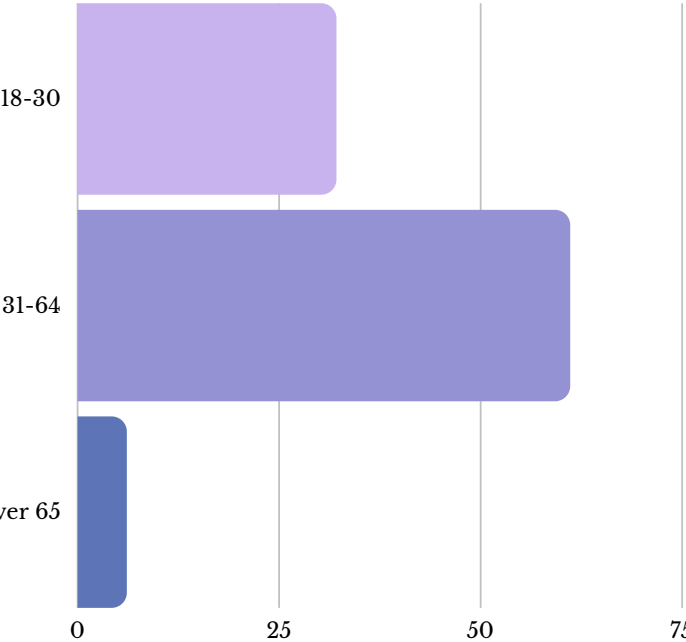
of survey respondents were people living with epilepsy taking the survey on their own behalf

**23%**

of survey respondents were loved ones of people living with epilepsy taking the survey on behalf of a person living with epilepsy

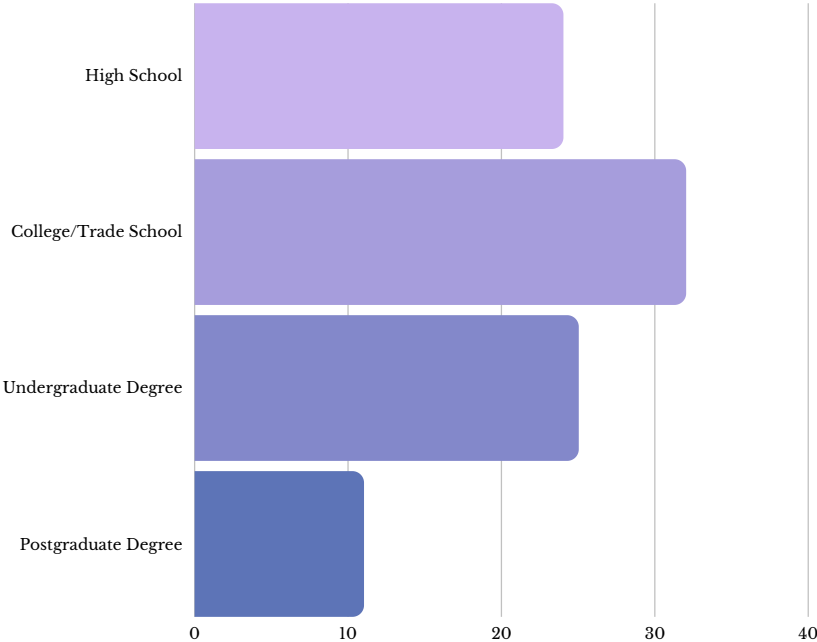
# AGE OF RESPONDENTS

32% of respondents were aged 18-30, 62% of respondents were aged 31-64 and 6% of respondents were over age 65.



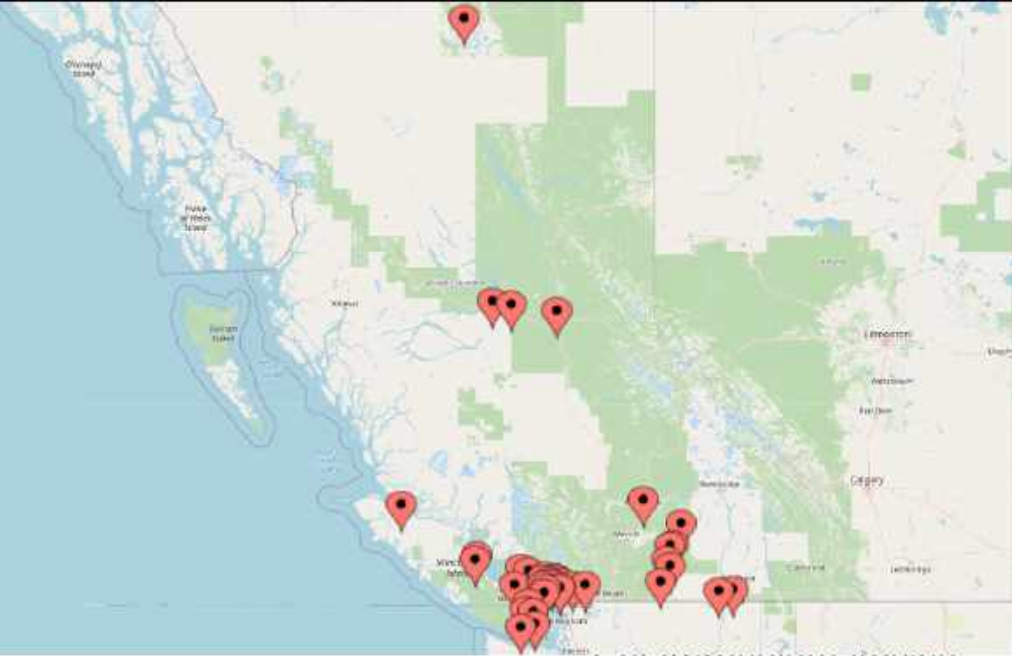
# EDUCATION LEVEL

26% of respondents completed a high school diploma, 35% of respondents completed a college/trade school degree, 27% of respondents completed an undergraduate degree and 12% of respondents completed a postgraduate degree.



# WHERE THEY LIVE

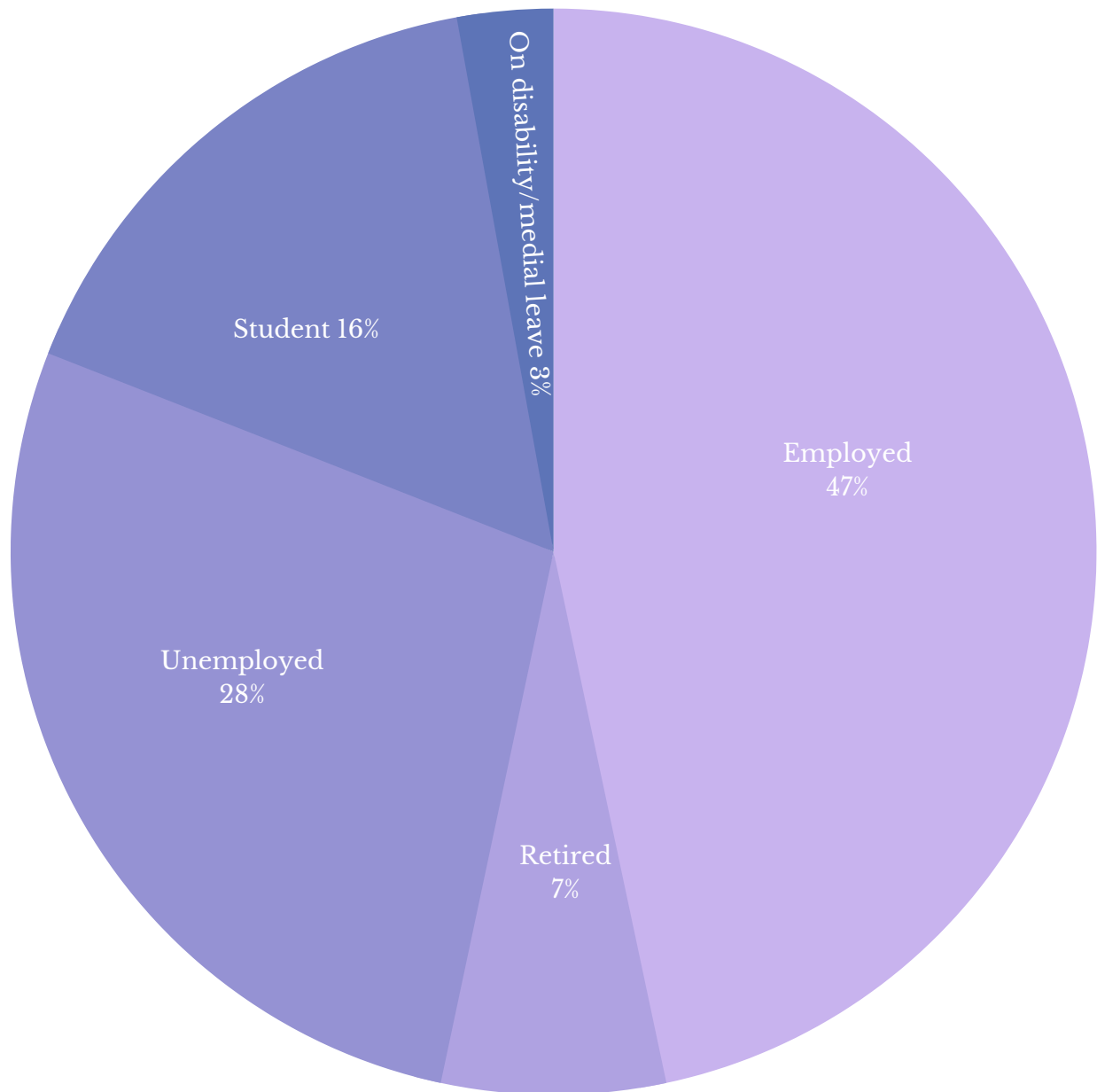
Respondents came from cities across British Columbia including Burnaby, Casablanca, Chilliwack, Christina Lake, Cobble Hill, Coquitlam, Courtenay, Cumberland, Delta, Fort Fraser, Gibsons, Kamloops, Kelowna, Keremeos, Langley, Langley Township, Maple Ridge, Mission, Nanaimo, New Westminister, North Vancouver, Penticton, Port Coquitlam, Port McNeill, Prince George, Richmond, Rossland, Salt Spring Island, Sechelt, Sidney, Sooke, Summerland, Surrey, Tsawwassen, Vancouver, Vanderhoof, Vernon, Victoria and West Kelowna.



# 48%

of respondents reported experiencing financial difficulties to feed themselves; to pay for their Anti-Epileptic Drugs (AEDs); and to pay for their bills, housing, etc.

# EMPLOYMENT STATUS



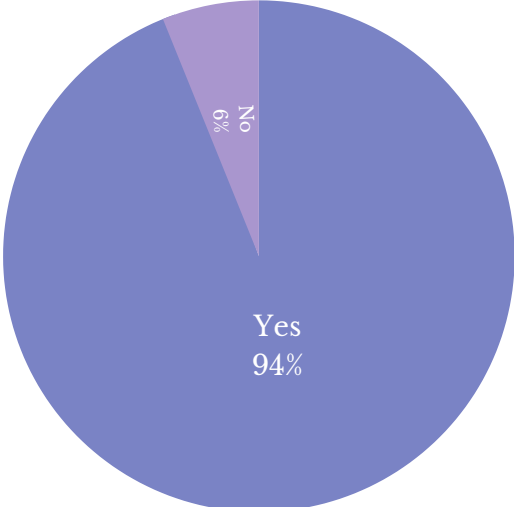
**"I am recovering from epilepsy brain surgery."**

**"Irregular contract work."**

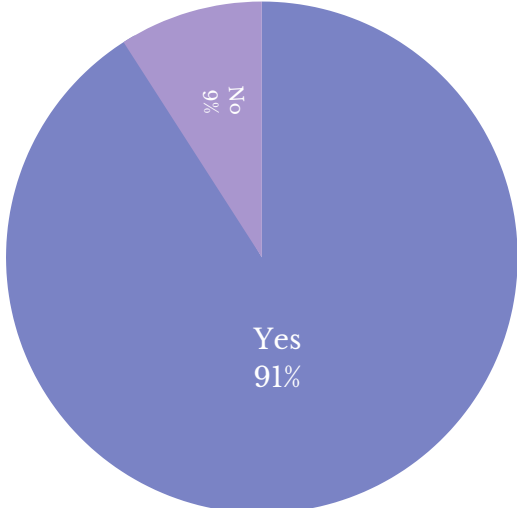
**"I worked for 21 years at a company and was released due to my epilepsy diagnosis."**

# EFFECT ON MENTAL WELL-BEING - ANXIETY

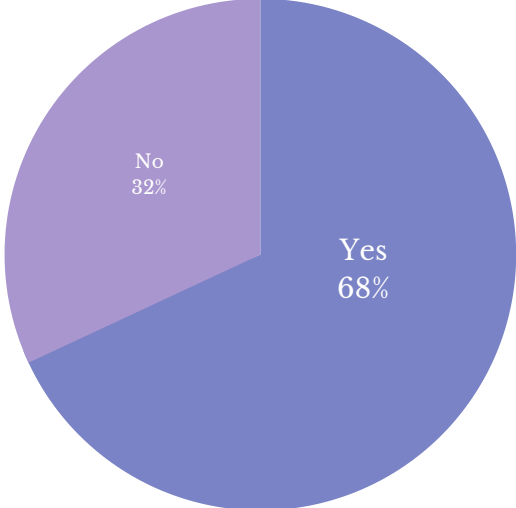
I FEEL TENSE OR WOUND UP



WORRYING THOUGHTS GO THROUGH MY MIND

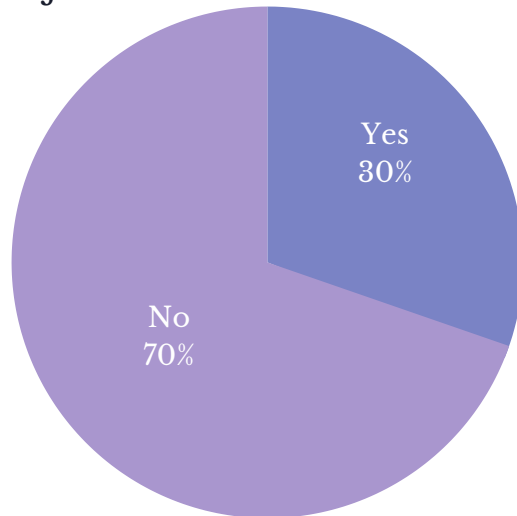


I GET A SORT OF FRIGHTENED FEELING

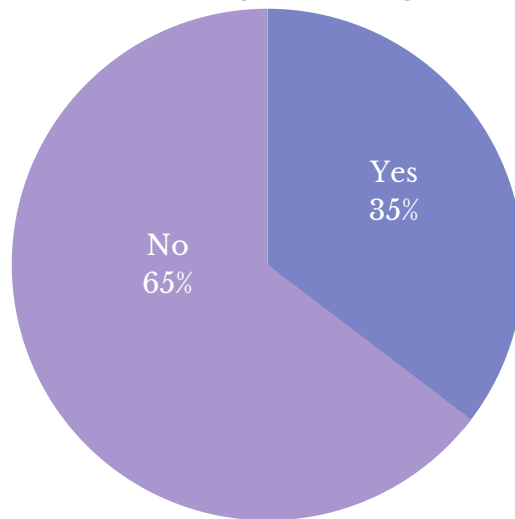


# EFFECT ON MENTAL WELL-BEING - DEPRESSION

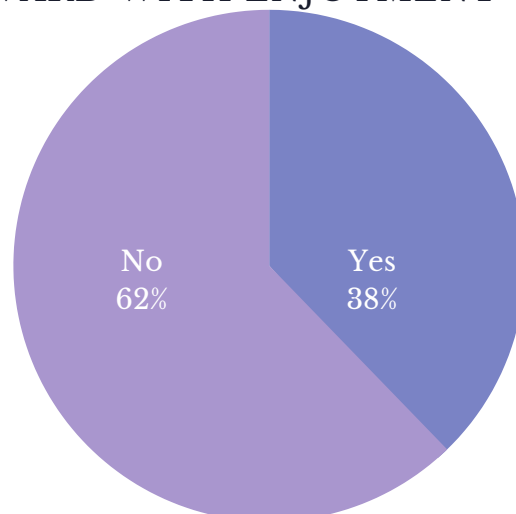
I STILL ENJOY THE THINGS I USED TO ENJOY



I FEEL CHEERFUL



I LOOK FORWARD WITH ENJOYMENT TO THINGS





# INFORMATION ON THE COVID-19 PANDEMIC

**13%**

of respondents had been tested for COVID-19 during the COVID-19 Pandemic

**69%**

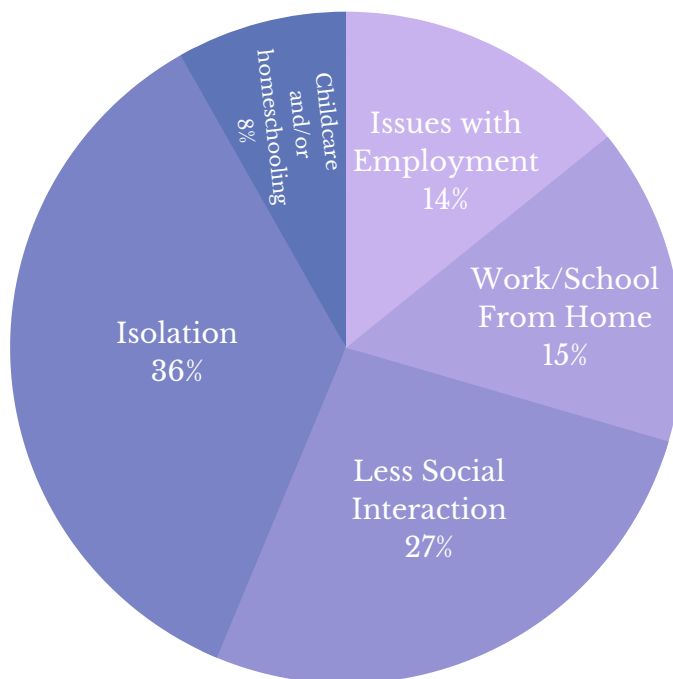
of respondents reported that a "Stay At Home" advisory was put in place due to the COVID-19 Pandemic in the city in which they live

**65%**

of respondents feared that their epilepsy and/or seizures put them at a higher risk of contracting COVID-19.



# HOW DID COVID-19 AFFECT YOUR DAILY LIFE?

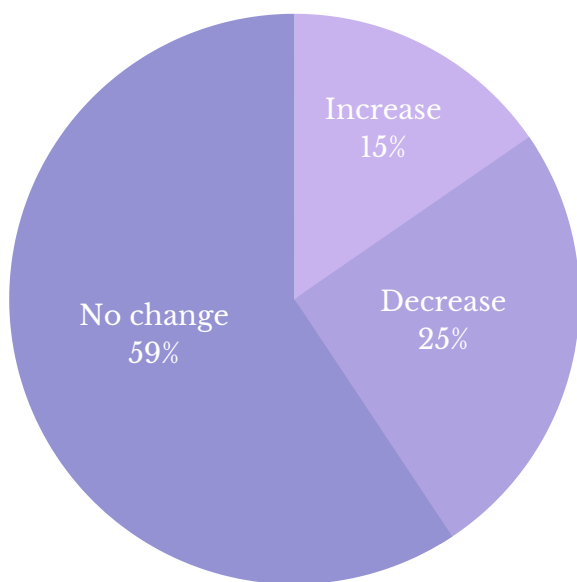


**"I was alone no support with epilepsy diagnosis."  
"Lack of social contact, no family doctor to consult with."  
"I was less willing to take public transit."**

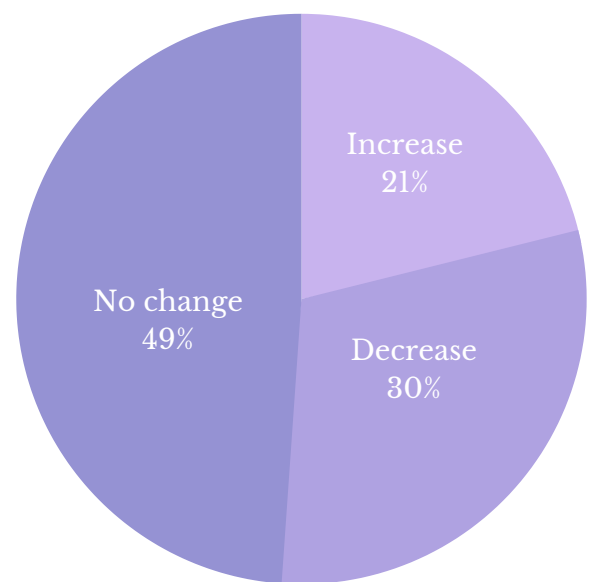


# HOW DID COVID-19 IMPACT YOUR FINANCES?

## INCOME



## SPENDING



# EFFECT OF THE COVID-19 PANDEMIC ON SEIZURES

**22%**

of respondents experienced an increase in their seizure activity due to the stress associated with the COVID-19 Pandemic

**38%**

of respondents experienced difficulty in filling their prescriptions due to the COVID-19 Pandemic

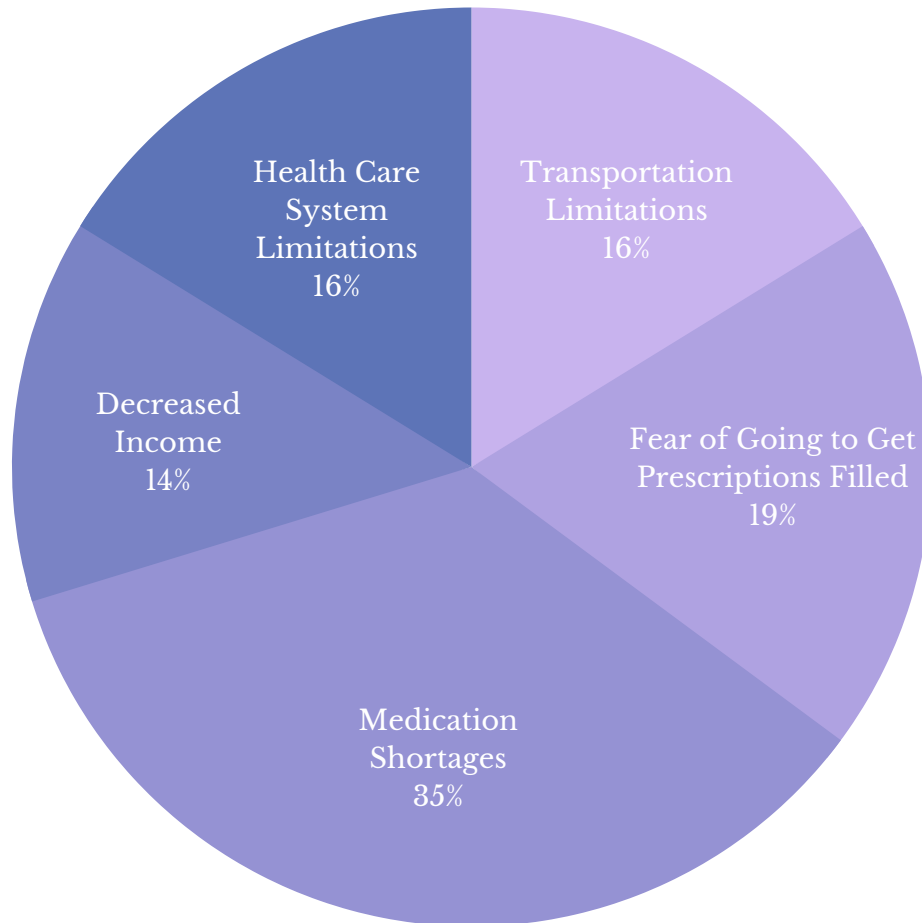
**96%**

of respondents are currently taking Anti-Epileptic Drugs in the treatment of their epilepsy

**69%**

of respondents are taking more than one Anti-Epileptic Drug in the treatment of their epilepsy

# DIFFICULTIES IN FILLING PRESCRIPTIONS



**5% OF RESPONDENTS EXPERIENCED AN INCREASE IN THEIR SEIZURES DUE TO ISSUES IN GETTING THEIR PRESCRIPTIONS FILLED.**

**"My doctor sent her pharmacy fax to the wrong place."**

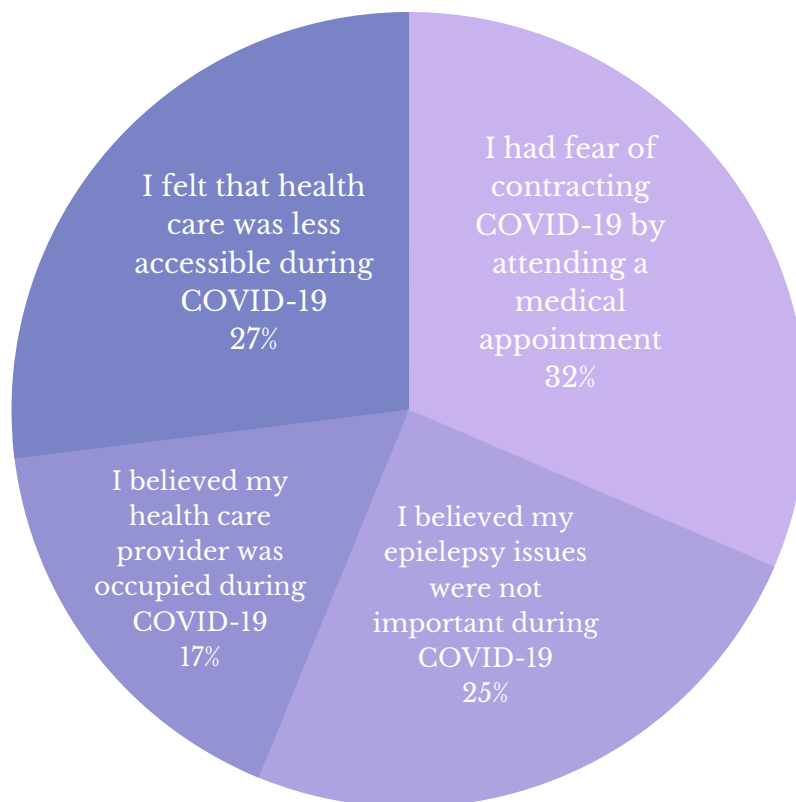
**"Unable to see a doctor to get a refill."**

**"I no longer take one of my medications because I cannot afford to pay out-of-pocket for it."**

# HEALTH CARE ACCESS DURING COVID-19

## 64%

of respondents experienced reluctance to seek medical care or emergency room visits because:



## 73%

of respondents had a visit planned with their health care provider

## 96%

of appointments took place as planned - either in person or through telehealth

## 4%

of appointments were cancelled either by the respondent or their health care provider



# 82%

of respondents were not aware that, in 2019, the BC Provincial Government awarded the BC Epilepsy Society only \$1.10 per person living with epilepsy per year for our programs and services.

**"BC DOCTORS AND HEALTH CARE PROVIDERS IN THE ADULT EPILEPSY SYSTEM HAVE A RIGHT TO THE SAME TREATMENT OPTIONS AND THERAPIES TO PROVIDE AN OPTIMUM STANDARD OF CARE FOR THEIR PATIENTS LIVING WITH EPILEPSY AS SEEN IN THE REST OF CANADA."**

**-Kim Davidson, CEO & Executive Director. BC Epilepsy Society**

## **ABOUT THE BC EPILEPSY SOCIETY**

The BC Epilepsy Society is a provincially incorporated non-profit organization and a federally registered charitable organization dedicated to serving the over 50,000 people living with epilepsy in BC and their families, friends and loved ones.

### **MISSION:**

To empower, educate and support British Columbians living with epilepsy and their families, and support research to make their lives easier.

### **VISION:**

Improving Lives. Inspiring Courage.



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