

COVID-19 Pulse Survey

Input from the Community Affected by the Epilepsies

The voices of our community matter. From April 20 to May 16, 2020, the Epilepsy Foundation surveyed our community asking about their experiences and challenges during the COVID-19 public health emergency and pandemic. This survey was distributed through the Epilepsy Foundation's communications channels, and was not randomized.

This report provides a snapshot of the community response to the survey during the early days of the COVID-19 pandemic. This information will help the Epilepsy Foundation provide better support during this critical time. We thank everyone who took the time to respond.

More information: [Epilepsy.com](https://www.epilepsy.com)

24/7 Helpline: 1.800.332.1000

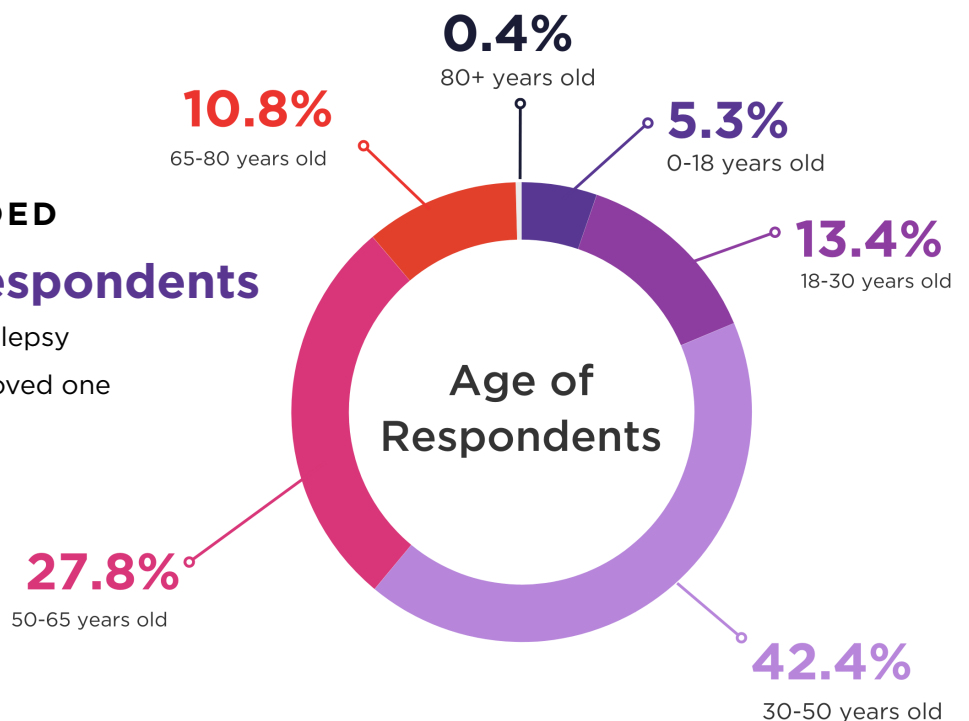


WHO RESPONDED

Over 600 respondents

75% person with epilepsy

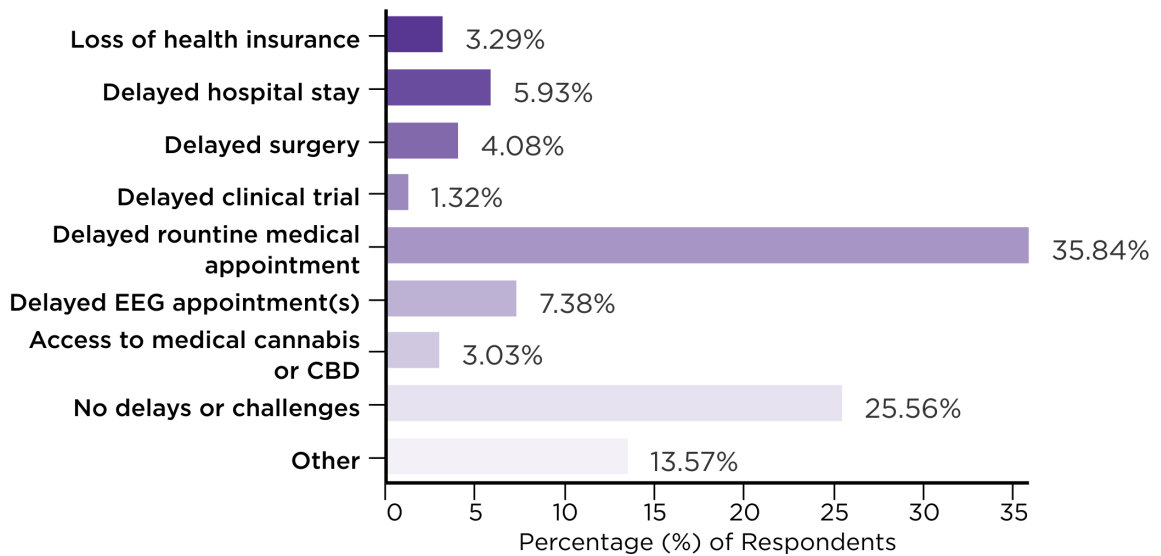
25% answering for loved one



19%

of respondents asked to be and were directly connected to an Epilepsy Foundation representative for support

Q: HOW IF AT ALL HAS COVID19 CREATED CHALLENGES FOR YOU?



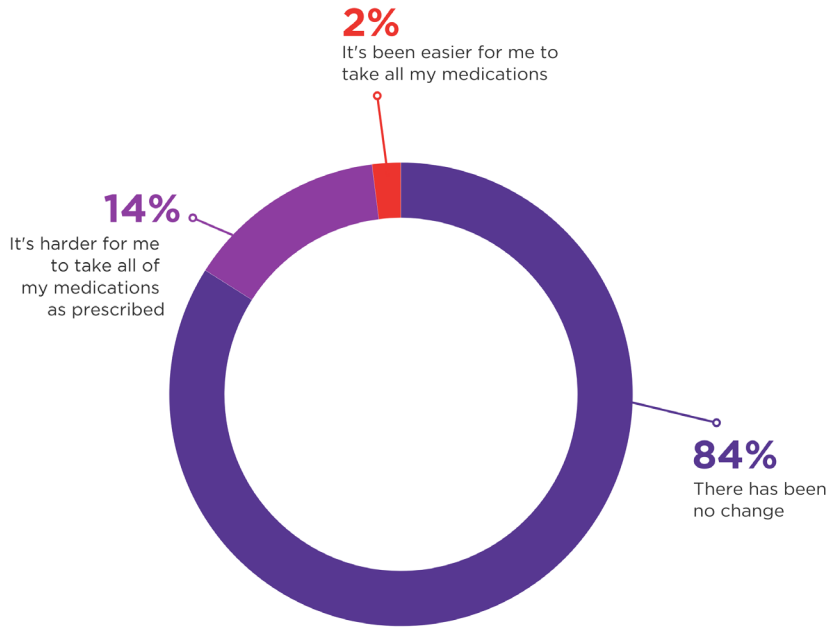
Top 20 words shared to describe challenges



Other challenges shared

- “ ...Before COVID-19, I was getting medication for free from the government hospital. Now there is no transportation allowed to the one I can access. Private pharmacies are too expensive.
- “ Delays in repeat prescriptions being processed due to lack of pharmacy staff
- “ It delayed all my health appointments and procedures not just epilepsy.

Q: HOW HAS COVID-19 IMPACTED YOUR ABILITY TO TAKE YOUR MEDICATIONS?



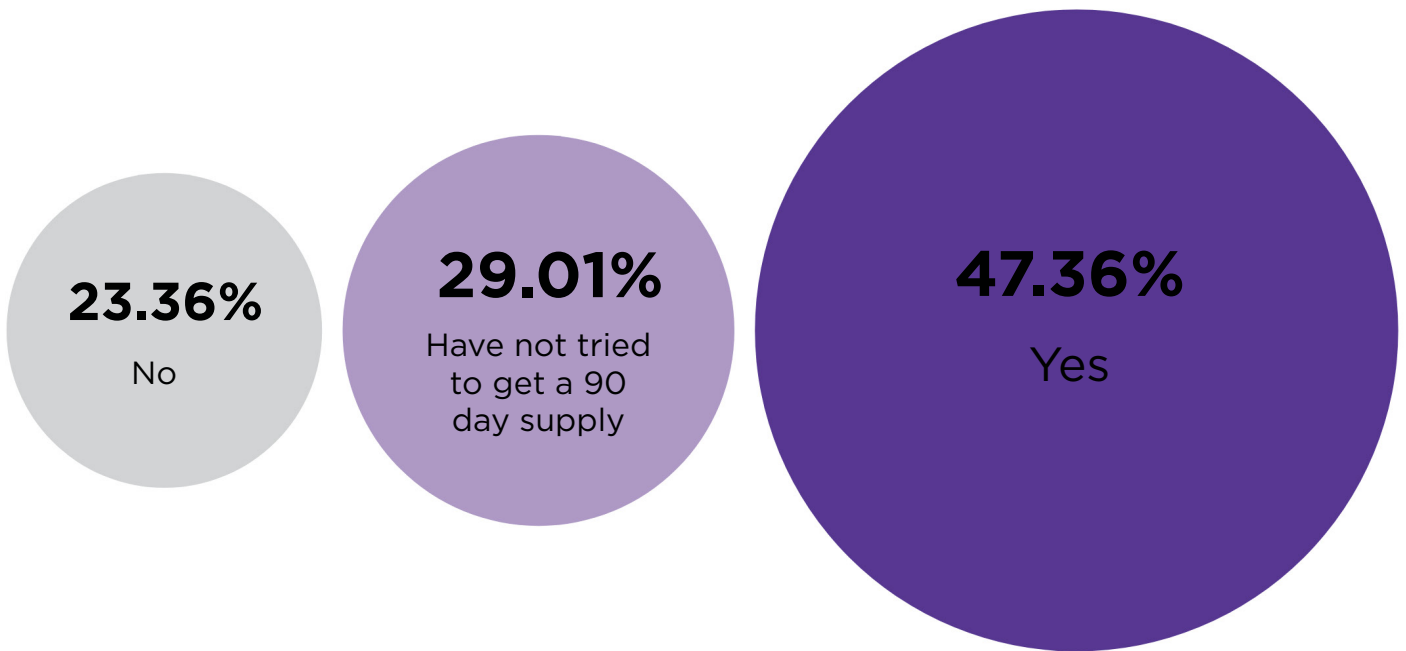
Top 20 words shared to describe impact on medications



Other challenges shared

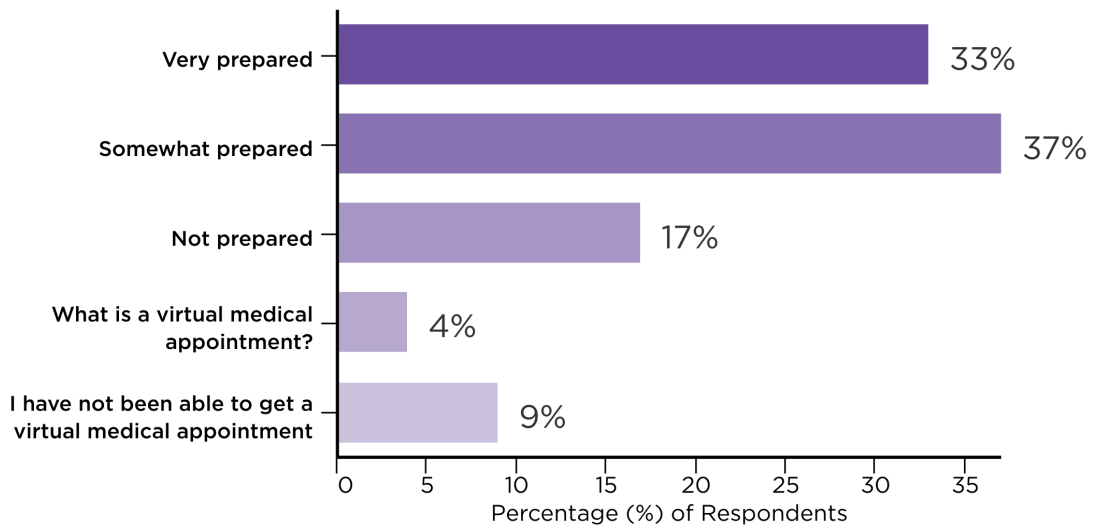
- “ My wife is now on furlough and will no longer have benefits.
- “ Loss of Insurance and new insurance needed to approve but they don't cover it. I'm trying to get a pre-authorization with the assistance from my neurologist.
- “ My work schedule was changed and I had to adjust the time I take my medications.
- “ Pharmacy usually delivers them but they've cut back.

Q: HAVE YOU BEEN ABLE TO GET A SUPPLY OF UP TO 90 DAYS OF YOUR ANTI-SEIZURE MEDICATIONS?





DURING COVID-19 PANDEMIC, DOCTORS ARE OFFERING VIRTUAL MEDICAL APPOINTMENT OPTIONS. DO YOU FEEL PREPARED FOR A VIRTUAL MEDICAL APPOINTMENT?



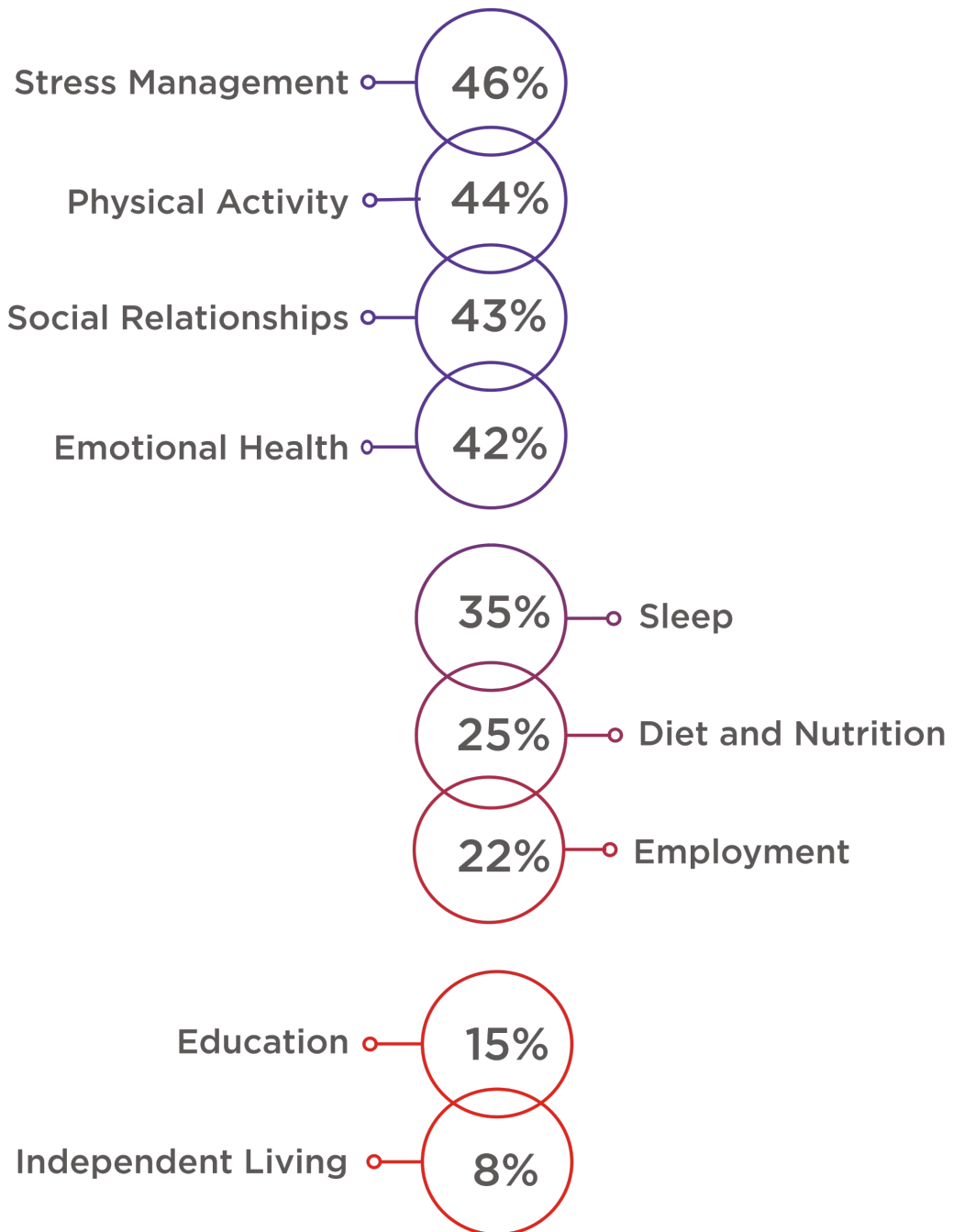
Top 20 words shared to describe worries about virtual appointments



Other challenges shared

- “ Doctor cannot check VNS settings with a virtual appointment
- “ Ability to confirm start of appointment.
- “ Ability to get local lab work in advance
- “ Internet service.
- “ It doesn't feel like any doctor is taking the time like they do in office

Q: HAVE YOU BEEN NEGATIVELY IMPACTED DUE TO COVID-19 BY ANY OF THE FOLLOWING ?



Q: WHAT IS YOUR BIGGEST CONCERN RELATED TO YOUR EPILEPSY CARE THROUGH THE COVID-19 PANDEMIC?

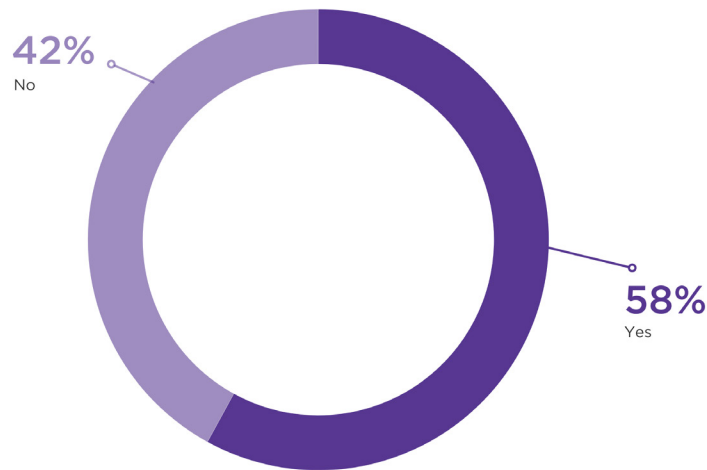


Top 50 words used in the free text response



- “ Having a grand mal seizure and going to hospital without wife or daughter. I am unable to answer questions and very confused for days and agitated post seizure. My family being there to answer doctor questions will make things easier and safer for me.
- “ Being examined by a doctor. Some appointments can be virtual. Most need to be in the examining room, so we can be examined. How can the doctor take my blood pressure w/out us being together? Neurologists ask for us to look straight ahead, and check our peripheral vision, reaction time, see how well I can walk in a straight line, etc.
- “ Having to take public transportation with the spreading of the virus in trains and buses.
- “ Fear my son won't be able to get his medication.
- “ lot of local clinics closed, requiring longer distances to doctor appt and pharmacy
- “ Me having a big seizure that doesn't stop and needing to go to the ER. Trying to avoid the emergency room if possible.
- “ How to transition back into world especially in close contact programs, caregivers and stay safe?

Q: HAVE YOU BEEN ABLE TO ACCESS MENTAL HEALTH AND/OR SOCIAL SERVICES (EITHER NEW OR CONTINUATION SERVICES) YOU FEEL YOU NEED?



Top 20 words shared to describe how mental health service support has been impacted



Other challenges shared

- “ My therapist has not offered online appointments
- “ Looking for education on financial aid
- “ Not really sure how to deal with it or who to call
- “ Not able to go to group activities to learn and feel wanted
- “ So busy with kids’ schoolwork, taking care of my kids and working ... I have to be strong for my kids
- “ Doctors are in another state so I can’t see them

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