

**Three Minute Article for Parents**

## Advice to caregivers of children with epilepsy during the Covid-19 pandemic

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Neurological diseases commonly require long-term care. Epilepsy is one such disorder due to its need for regular review and prescription refill. The Covid-19 pandemic resulted in an initial abrupt halt followed by subsequent significant limitation of healthcare facilities required for its satisfactory control. Caregivers bear significant stress and anxiety when regular services are interrupted, the impact being greater when the affected person is a child.

A research study was conducted in 2020 after the first wave of Covid-19 among caregivers of children with epilepsy in Sri Lanka, to assess their response during the lockdown and preparedness for recurrence<sup>1</sup>. This was conducted among 140 caregivers attending paediatric neurology services in seven major hospitals in the island. A large majority of patients (87%) did not suffer from a change in their child's epilepsy control during the pandemic. However, many experienced hardships to maintain regular reviews and prescription refill. These included not receiving medications through the postal services (49%), inability to purchase the medications (57%), inability to reach a pharmacy due to restrictions on movement (60%) etc. Despite these difficulties, 87% of parents maintained the provision of anti-seizure medications to their child regularly.

The caregivers, the biological parent in 98%, demonstrated healthy self-management strategies to face similar lockdowns in the future. They were aware of the name of the child's epilepsy medication (88.6%), knew the doses prescribed (84.3%), were keen to maintain adequate supply of medications (72.5%) and tried to maintain extra supplies in case of an emergency situation (71%). They also indicated feeling confident of having access to medications (83%), being aware of how to contact their child's doctor (87%) and feeling confident about having help from the system (90.7%). Caregiver stress was measured using a self-rating stress assessment questionnaire. Stress was experienced only in 4% of the subjects. There was

no significant association between stress and economic strata or level of education, but the caregivers from rural backgrounds were more stressed than those in the city. Only 2.1% had accessed help through the internet to resolve their concerns related to epilepsy in their child.

Based on the study findings we encourage parents to be empowered regarding managing their child's epilepsy and become educated on essential information that will help overcome delays of prescription refill. This includes names, doses and prescription schedules of the child's medications. Creating contact with regional hospital or relevant clinic or even local pharmacy and maintaining extra supply of medications would help to avoid shortage of medications. Positivity, self-confidence and communication with other parents will help caregivers to overcome many hardships faced during this period.

### Reference

1. Wanigasinghe J, Jayawickrama A, Hewawitharana G, Munasinghe J, Weeraratne CT, Ratnayake P, *et al.* Experience during Covid-19 lockdown and self-managing strategies among caregivers of children with epilepsy: A study from low middle income country. *Seizure* 2021; **84**: 112-5.  
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