

A guide to caring for an epileptic patient

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Epilepsy is a chronic and debilitating disorder that impacts not only those with it, but also those who care for them. The term 'epilepsy' encompasses a group of neurological diseases, that is, conditions that affect the nervous system, characterized by epileptic seizures commonly called 'fits'. In India, there are about 10 million people living with epilepsy, and worldwide this number is as high as 100 million people.

Patients with epilepsy may have more than one type of seizure and may have other symptoms of neurological disorders as well. If there is some resulting disability or weakness, they may not be able to manage without help. In epilepsy, therefore, the role of a caregiver is very important.

A caregiver might be a parent, spouse or a friend. The caregiver's responsibility includes keeping the patient safe during a seizure, calling for medical help, giving first aid and emergency medication. They need to stay with the patient and take them home or to a doctor safely after a seizure. They also need to help the patient with regularly taking their medicines, particularly in the case of young patients. It helps if there is a routine of taking the anti-epileptic medicines at fixed times.

During the current COVID-19 pandemic, the caregiver must ensure to keep themselves and the patientsafe from the virus, and practice all the government advised safety measures such as social distancing, regular hand washing /sanitisation, etc. The following precautions must be taken -

- Have sufficient medicines at home for the patient
- Keep emergency numbers in handy in case of any unexpected incident
- Be in touch with your doctor through tele-consultations
- Manage stress and anxiety
- Avoid changing or stopping medications without consulting your doctor

Being a caregiver requires the person to juggle a number of skills including technical tasks such as dealing with medical equipment, giving emotional support, being able to adapt if the patient's needs change, and working with doctors involved in the patient's care. These roles are usually in addition to the other demands on a caregiver's time from his or her family, other relationships, duties at work, home and social life, not to mention his or her own health. The caregiver should be careful not to neglect these aspects of their own life, and strive to maintain a balance.

People with epilepsy may also have other associated conditions that require additional care. Since the seizures can be infrequent or not seen by others, epilepsy can be a 'hidden' condition. For some people, living with epilepsy can have a psychological impact and the stress, depression and mood changes may also affect the caregiver. Caregivers should be careful not to let any emotions like guilt, anxiety or helplessness affect them. It is important for a caregiver to look after themselves and spend some time on their mental, emotional and physical well-being. The caregiver also needs someone to talk to and not feel alone and isolated in his situation. They should take time for self-care: good eating habits, consistent exercise, plenty of restful sleep. Relaxing through deep breathing and meditation can help. It also helps to find a creative outlet through art, writing, and crafts. Epilepsy is an entirely manageable condition and both patient and caregiver can work together to find a routine that helps both of them go through their daily lives smoothly.

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