



## STRATEGIES FOR LIVING WELL WITH EPILEPSY

### SEIZURE JOURNAL:

Keeping a seizure journal is a simple task that many people living with epilepsy forget to do. A Seizure Journal is an on-going daily recording of your seizure activity. People choose to record this information in a variety of ways; however it's not the format that is most important; it's the content.

Your Seizure Journal is the place where you record all information about your seizures. Your family, friends and co-workers are your best resource for the information you will need to record. Important information to include should be the date, time, and length of the seizure. What did it look like? Did I experience an aura? Was there anything different about this seizure than my other seizures? What was I doing when I had the seizure? Did I miss taking my medication(s)?

When making an entry into your seizure journal it is best to go back as far as one week prior to your seizure and ask yourself these questions:

- Have I been getting my usual amount of sleep? Have I been over-tired or up late?
- Have I been eating healthy meals at regular times? Have I been avoiding excessive caffeine and alcohol?
- Have I been experiencing more stress than usual?
- Has anything out of the ordinary been going on in my life?

It is important to record the answers to this information as well. Often seizures can be the result of a combination of factors. Together with the help of your Seizure Journal and your epileptologist, you may be able to determine what factors serve as triggers for your seizures, and work to avoid them.

The Seizure Journal is also important for tracking the success or failure of medication as well as any changes in your seizure activity that your epileptologist should be aware of. A free downloadable Seizure Journal template is available at [www.epilepsydurham.com/pamphlets.html](http://www.epilepsydurham.com/pamphlets.html). An free online journal is also available at [www.seizuretracker.com](http://www.seizuretracker.com).

### QUESTION LOG:

Appointments with our health care practitioners can be many months apart. During the time between doctor visits, you will likely have many questions about your seizures and how to manage them. This is why we suggest starting a Question Log. All you need is a blank lined notebook, available at most dollar stores.

Your Question Log is different from your Seizure Journal. It is the place where you record all the questions as you have them in between your doctors' appointments. With long periods of time between visits, it is easy to forget questions that you or your family may have. An effective strategy to avoid forgetting these important questions is to record them in your Question Log. We suggest writing only one question at the top of a page, and leaving the remainder of the page blank. During your next visit with your doctor, you can read your question directly from the log. Record the doctors' answer in a way that you can understand in the blank space on the rest of the page.

It is also easy to forget the answer to the question you have been waiting months to hear. These appointments can be both short and stressful. You and your health care practitioners are in partnership working towards well managed epilepsy. Express this to your doctor, and how important it is for you to write down their answers. Remember to express your appreciation for their patience. If you have the type of seizures that don't respond well to medications, remember to ask your physician about possible surgical options. Some of the most difficult seizures to control are amongst those that can be readily treated by surgery.

## **EMERGENCY RESPONSE ACTION PLAN:**

Epilepsy or a seizure disorder may present itself in many forms and can represent many challenges for parents, caregivers, and educators. Having an Emergency Response Action Plan may aid in providing assistance for those who cannot advocate on their own when a seizure occurs and emergency assistance is required.

Take the Lead in Your Seizure Management. For a suggested checklist for developing your personal Emergency Response Action Plan please visit [www.epilepsydurham.com/frp.html](http://www.epilepsydurham.com/frp.html) or ask an Epilepsy Durham Region staff member for guidance.

## **MEALS AND MEDICATION:**

We all know that we *should* eat healthy well-balanced meals at regular times every day. For the person living with epilepsy, this is especially important. Fluctuations in blood sugar levels can affect our tendency to have a seizure and potentially the effectiveness of medication.

Taking seizure management medication as directed is also important. If you have concerns about your medication or possible side effects always consult a physician before stopping medication or going 'cold turkey'. Stopping a seizure management treatment without being properly managed may result in brain damage and other serious side effects.

## **SELF ADVOCACY:**

What does it mean to live well with epilepsy? It means healthy, fulfilled daily living. It means open, knowledgeable communication about epilepsy at home, at school, and at work. It means dispelling fear and stigma surrounding epilepsy through education and advocacy. Living well with epilepsy is an active choice you can make for yourself.

You are not defined by your seizures. Having seizures is one aspect of your multi-faceted life. One of the most common challenges that people living with epilepsy face is a lack of awareness. The good news is that *you* have the power to change these attitudes. Stay educated about epilepsy. Learn the terminology. When you speak about epilepsy in a calm, educated, and positive manner people will respond in the same way.

If there is an opportunity to attend a political function, let your views be known and how you would like to maintain and improve services for those with epilepsy. Those that have been elected officials represent you; educate them about epilepsy.

Most importantly, you must take responsibility for your own well-being. By doing very simple things like keeping your Seizure Journal, your Question Log, devising an Emergency Response Action Plan, eating well and working with your doctors to find the optimal seizure management treatment, you are on your way to living well with epilepsy.

Epilepsy Durham Region can help you. Find out about upcoming educational and fund raising events by contacting Epilepsy Durham Region or visiting: [www.epilepsydurham.com/news.html](http://www.epilepsydurham.com/news.html).

## **STAY EDUCATED. STAY INVOLVED. LIVE WELL.**

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