

SINGAPORE EPILEPSY FOUNDATION *IN* Newsletter



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Editorial

Different approaches can be used for the treatment of epilepsy. The best known are antiepileptic medications. Unfortunately sometimes medicines cannot sufficiently control recurrent seizures and additional approaches can be sought. One of these is a treatment called vagus nerve stimulation. This method takes advantage of the body's own antiepileptic defenses by stimulating the vagus nerve which in turn has an antiepileptic effect on the brain. This edition of the Singapore Epilepsy Foundation Newsletter explores the way this treatment works and its uses.

We have now reached the end of our ABC education series of epilepsy which first started at the end of 2000! In this end of the alphabet edition, the topics range from Uncal seizures, Valproate, to World Wide Web sites for lay information on epilepsy and Zonisamide. We hope that this series has been both useful and informative.

The Singapore Epilepsy Foundation (SEF) website (www.epilepsy.com.sg) is up-and-running! Don't forget to check it out to keep yourself updated on the latest developments regarding epilepsy in Singapore. The site also contains free copies of all the past SEF newsletters!

Wishing you a good start to the New Year!

The Editor

Activities and News

Christmas Party Y2002

A Christmas Party organised by Singapore Epilepsy Foundation (SEF) was held on 21 December 2002 at Singapore General Hospital Lecture Theatre. Attended by 50 epilepsy patients and their family members, it was an eventful day. They had enjoyed themselves through games and some even participated in the singing session. We look forward into seeing you at our next party!

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Epilepsy education

ABC of Epilepsy

Uncal Seizures

The uncus is part of the medial and inferior part of the temporal lobe of the brain. It is associated with pathways for smell recognition. For this reason, seizure activity originating from this part of the brain may result in olfactory hallucinations. Often during a seizure the person will smell odors that are actually not there. Typically the smell is described as being unpleasant. These types of seizure are not infrequently due to an underlying brain tumor.

Vigabatrin

This is an antiepileptic medication which is mostly used in children. There is strict regulation regarding its use as about 25% of patients will develop visual problems.

West syndrome

This is another name for a condition better known as infantile spasms. The condition represents a number of brain diseases which result in severe epileptic seizures from early on in life and are often difficult to treat.

World wide web sites for lay information on epilepsy

Singapore Epilepsy Foundation (SEF): www.epilepsy.com.sg

American epilepsy society (AES): www.aesnet.org

Canadian league against epilepsy: www.clae.ca

International league against epilepsy: www.who.ch/ina/ngo088.htm

Zarontin

This is the trade name for the antiepileptic called ethosuximide. This medication is purely used for absence type of seizures. It is not useful for the treatment of Generalised Tonic Clonic Seizures.

Zonisamide (Zonegran is the tradename)

Zonegran is indicated for use as an adjunctive therapy for treatment of partial seizures (or focal seizures) in adults with epilepsy. Zonegran, which has been available in Japan since 1989 under the trade name of Excegran, is available on the U.S. market since May, 2000. It is not registered for use in Singapore.



www.epilepsy.com.sg. look out for more updated news and activities there.



Vagus Nerve Stimulation

- a treatment option for a difficult to control epilepsy

Professor Dr. C.E.Elger, Epilepsy Clinic, University of Bonn, Germany

Vagus nerve stimulation (VNS) requires a simple surgical procedure and offers benefits for many patients with refractory, or difficult-to-control, epilepsy; including significant improvements in quality of life. In principle, electrical stimulation of the vagus nerve sends signals to the brain that have an ameliorating effect on the causes of epilepsy where they begin. The vagus nerve is easily accessible, on the left side of the neck; 80% of its fibres transmit messages to the brain; and it has no pain transmitting fibres.

VNS Therapy has been used to treat over 15,000 patients worldwide. Almost 6,000 of these patients, treated by over 1,000 doctors at some 850 treatment centres, have been monitored. This is a well-studied and comprehensively documented option for the treatment of difficult-to-control epilepsy.

Who is it for?

1 out of 3 patients suffer from difficult to-control or medically refractory epilepsy. The first treatment option is an AED, with 40% of patients achieving control after the first one prescribed. If that does not work, then the odds of gaining control with AEDs diminish. By the third drug only 5% will benefit. The remaining patients have difficult to-control epilepsy and are candidates for VNS Therapy, whether they have partial, primary or secondary generalized epilepsy.

Difficult-to-control epilepsy is a chronic, often lifelong problem. It implies much more than suffering from seizures, and most patients have

a poor quality of life. As a result some patients may stop taking their medications. Difficult-to-control epilepsy requires a long-term treatment that offers the benefit of being 100% complaint.

VNS Therapy is an adjunctive therapy (one that is used in addition to another type of therapy, usually medication) and is suited to patients of all ages, and where the patient has mental or developmental difficulties. VNS Therapy is an alternative for patients who are not candidates for resective epilepsy surgery or for patients where surgery has not been successful.

The equipment

The basis of VNS Therapy is a generator, shaped like a pacemaker, which sends a tiny electrical signal along a fine electrode to the vagus nerve. The signal is intermittent, usually 30 seconds in every five minutes. The exact pattern can be adjusted by the physician to suit the individual by using a remote control device and simple computer program. The patient is given a small magnet that can be used to switch and control the generator.

The procedure

Surgery takes between one and two hours. The generator is implanted in the upper chest, through a short incision near the left shoulder. A second incision is made on the neck. This can be within a natural skin fold, giving a good cosmetic outcome. It is a simple procedure with minimal complications and often is carried out under local anaesthetic on an outpatient basis. Many patients are attracted, as it does not involve surgery to

the brain, or even the head.

The results

Once the generator and electrode are in place and activated, stimulation can be adjusted for maximum patient benefit. This takes place during outpatient visits over the following few weeks. Patients treated with VNS Therapy show a range of benefits. Interestingly, many VNS Therapy benefits increase over time including seizure control and quality of life. For example, 56% of patients report improved alertness after three months and over 60% after a year. Similar increases are found in post-ictal improvements and cognitive aspects such as verbal skills and memory.

While benefits improve, the slight side effects decrease. Typically, the side effects are hoarse voice, throat discomfort, a cough or laboured breathing. Some patients report no side effects at all and when they do occur it is only during the stimulation period. Also, it is rare for a patient to

report more than one or two. They generally decrease over time and often disappear within a year. As a result of these long-term benefits, 3 out of every 4 patients continue with VNS Therapy after 3 years.

The magnet

The magnet is benefit for patients who are aware of an impending seizure. Triggering the generator, by passing the magnet over it, can diminish the effect and length of the seizure or even avert it totally. This can also be done by a parent or by a carer. Many side effect problems can be overcome by the using the magnet. For example, the generator can be switched off to eliminate voice effects while singing or speaking in public. Some patients who had difficulty swallowing before VNS Therapy find switching the generator off is of help while eating.

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First Aid of Seizures

At every SEF meeting we still hear the same sad stories about inappropriate treatment of seizures by the general public. The most common and most dangerous misperception of the general public is that during a seizure something could be inserted into the mouth. **THIS IS A HORRIBLE MISTAKE** and can cause severe injuries to the person suffering the seizure as well as to the person wrongly inserting the object. We now recommend that each person suffering from seizures should tell friends and relatives **Not** to insert anything into the mouth but to follow the below recommendations:

If you happen to witness a generalised convulsive seizures the most important thing is to make sure the person does not harm him/herself during or after the seizure.

- 1) Lie the person on his side in the recovery position.
- 2) Keep the airways free. Remove loosely fitting dentures and solid objects that may have been vomited up during the seizures.
- 3) **DO NOT** insert a spoon or any other object into the mouth as this will result in two things: Injury to the mouth and teeth of the person and potential injury to you! (the person will often bite as a reflex action and fingers may be severely damaged or even lost!!)
- 4) Do not restrain the convulsive movements as you may injure the person.
- 5) Call for medical help.
- 6) Time the duration of the seizure.

Epilepsy and Self Management

Four keys to successful self management

There are four factors that can help you become more effective in self management. They are working knowledge, personal awareness, confidence and taking responsibility.

1. Working knowledge

This means knowing the facts about epilepsy and understanding how they apply to you. Knowledge can take away stress and anxieties by helping you feel in control. It's up to you to find out as much as you can about your condition and what you can do to care for yourself. Try to keep an open mind about your epilepsy and if you are unsure about any aspect of it check with your doctor or Epilepsy Action. Sharing your experiences with others who have epilepsy is one way to learn more and can also help you feel less isolated.

2. Personal awareness

Your approach to your epilepsy can influence how you feel about yourself and how others perceive you. Above all you are a unique individual with your own size, shape, colour, age skills, talents and ambitions in life, who also happens to have epilepsy. Thinking of yourself as "an epileptic" or saying "I am an epileptic" as soon as you meet somebody defines you in terms of your condition. This can make it difficult to see the person behind the label. Epilepsy Action campaigns against the term 'an epileptic' - epilepsy is what we have NOT who we are!

Knowing you have epilepsy can change the way you think, feel and behave. But equally the way you think, feel and behave can change your epilepsy. Many people with epilepsy have noticed that their emotions and feelings affect how often they have seizures. So, if you are able to, learning to think positively and managing your emotions

may actually help reduce the number and severity of your seizures.

3. Confidence

Your confidence in yourself will influence your commitment to self management. You have epilepsy and from time to time it may cause problems. However it is vital not to use your epilepsy as an excuse. For example, "If it wasn't for my epilepsy I would be the managing director, a famous fashion model"... or whatever. Go for what you want to do and refuse to use epilepsy as a peg on which to hang all your discontents and worries.

It's true to say that it's not so much what happens to you in life that is important but how you deal with it. Try to think about the positive aspects of having epilepsy and concentrate on the things you can do rather than those you can't. For example not being able to drive may mean that you get to places quicker than if you were stuck in a traffic jam, you get more exercise, meet more people and can use the money you save on running a car to take taxis.

As a first step towards such positive thinking why not make a list of the things you can still do and of new things you intend to try?

4. Taking responsibility

Once you have learnt all there is to know about your epilepsy and are receiving the best possible treatment, you owe it to yourself and those around you to look after yourself.

There are several ways to do this:





- Take your medication as prescribed and make sure you understand what it does and why you need to take it.
- Know your triggers. Stress, fatigue, boredom, lack of sleep, too much alcohol and various other factors can all increase some peoples' tendency to have seizures. Learn which ones can affect your epilepsy and take steps to avoid them. It doesn't mean you have to live a boring life.
- Inform yourself about what work and leisure activities you can do (and what safeguards you must take) and which ones would be irresponsible. You will probably find that there's not much you cannot do.
- Understand the driving rules and, if your epilepsy prevents you from driving, try to accept it. It's tough, especially when your friends all drive cars. However, driving with active epilepsy is highly dangerous for you and those around you - don't risk lives.

Talking about epilepsy

There will be some people who need to know and some people you will want to tell about your epilepsy. It's best to present your condition in a matter of fact way without being over-dramatic or negative. While not everyone will react positively, the benefits of being open and honest about your condition are many. For example:

- It enables you to get the help you need if you have a seizure in their company. This puts you under less strain - especially if your epilepsy is not fully controlled. It helps other people to understand you - and epilepsy - better.
- It helps you get closer to people who are important to you - it's difficult to get close to someone if you are hiding something.
- It can reduce the anxiety of having a seizure when other people are around.
- It helps dispel some of the stigma and myths that surround epilepsy.

Having said all this it can still be tricky deciding who to tell, what to say and when to tell them. Those of us who have epilepsy find that in many cases it can be helpful to wait until other people have had the chance to observe us as people before talking about our epilepsy.

You and your doctor

Your doctor should encourage you to be a partner in your medical care and to play an active part in discussing your treatment. Sometimes we may have excellent treatment from caring, committed professionals. However, at other times we may feel our need for information and support are ignored. We need accurate knowledge about drugs and procedures, what choices there are and what the alternatives are if we want to make informed decisions.

If your doctor doesn't tell you what you want to know then ask. If you don't understand ask for the information to be explained. If necessary keep asking until you are satisfied that you have all the information you need. If your doctor is not forthcoming or you want to find out more, libraries, the pharmacy, books and, of course, Epilepsy Action, are good sources of information. If you wish to discuss something you have read in an Epilepsy Action booklet or on this site with your doctor, take a copy with you when you go for an appointment. This may help the doctor find out more information. Leave a copy with the doctor and you could be helping other patients with epilepsy too.

What you should be able to expect from your doctor

Ideally your doctor should:

- Answer your questions and give you as much information as you ask for
- Give you treatment options and let you join in the decision making
- Help you steer your way to various professionals who can help you
- Actively listen to what you have to say
- Know his/her own limits and be honest about the limitations of treatment.

If you don't feel you are getting the service you need from your doctor it may be possible to change or ask for a second opinion.

This article was retrieved from Epilepsy Action's website: www.epilepsy.org.uk.

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