

SEIZURES AND TEENS: When Medicines Don't work— DEVICES & DIET

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Summary

When medicines don't work, the search for seizure control should not stop. Special diets or medical devices may be recommended to help control seizures. While not a cure for epilepsy, they may be able to help, especially for those who are not candidates for surgery or when surgery doesn't work. This article provides an overview of the devices and diets in current use and the practical aspects of using these in epilepsy management.

Introduction

While antiepileptic drugs (AED therapy) are the mainstay of epilepsy treatment, interest in non-medical approaches has increased. The most common non-medical treatments currently used are vagus nerve stimulation and the ketogenic diet. Other devices and diets are being studied and may provide promising options in the future. While avoiding potential side effects of medications, devices and diets may also have side effects or safety concerns that must be considered.

VAGUS NERVE STIMULATION

What is vagus nerve stimulation and how does it work?

Vagus nerve stimulation (also called VNS or VNS Therapy) is a way of providing electrical stimulation to the brain to treat seizures that do not respond sufficiently well to drug therapy. VNS Therapy consists of a device (called the generator), about the size of a stopwatch or silver dollar, which is implanted surgically under the skin on the left side of the chest or underneath the left arm. A second incision is made in the left side of the neck allowing a very thin flexible wire or electrode to be wrapped around the vagus nerve. The electrode is then threaded underneath the skin and connected to the generator in the chest. Surgery to place a vagus nerve stimulator is usually done on an outpatient basis using general anesthesia. The procedure usually takes only 60 to 90 minutes, but the patient will need to remain a few hours in the hospital for observation. In some situations, a person may need to stay overnight in the hospital after the surgery. After recuperating at home for one to two weeks, people return to see their neurologist and nurse and have the device turned on.

VNS Therapy works by delivering intermittent low levels of electrical energy or stimulation to the left vagus nerve, which then sends signals to the brain. The way it works to reduce seizures is poorly understood, but it may somehow interfere with the spread of seizures in the brain. Research has shown changes in blood flow and certain sub-

stances in the brain in association with VNS Therapy that appear to be important in stopping seizures.

Who is VNS Therapy designed for?

VNS Therapy has been approved by the Food and Drug Administration to treat partial seizures in people who are 12 years of age or older but has also been used in children of all ages. The therapy is indicated for use in people who have partial seizures that don't respond well enough to medical therapy and who are not candidates for brain surgery or for those who still have seizures after surgery. VNS Therapy is not a substitute for medical therapy and is considered an "add-on" treatment, which means that it is used in addition to medications. However, some people may be able to lower doses or the number of medicines that they take if VNS works for them. This device has also been approved for the treatment of major depression that does not respond to treatment in people 18 years or older.

While VNS is considered safe and effective, it is not a treatment for everyone. People considering this procedure should meet with their neurologist and primary care doctor to make sure that no other medical problems would interfere with the VNS and that VNS (and the surgery) would not aggravate any other medical conditions. For example, it may not be appropriate for some people with conditions affecting the heart, lungs, or stomach; for people with only one vagus nerve (normally, people have two vagus nerves, one on each side of the neck); and for people who cannot tolerate possible side effects of the device.

How is the VNS programmed?

The VNS is "turned on" or programmed to deliver specific amounts of stimulation. This programming is done in the outpatient clinic; the treating provider (usually a doctor or nurse) can set the amount or dose of stimulation by holding a hand-held wand over the generator in the chest. This wand allows the programmer to "talk to" the device to make sure that it is working properly and adjust the stimulation amount appropriately. Just like a medicine, the amount of stimulation is started at a low dose and increased gradually. There are many different settings that can be adjusted as indicated by how the teen is responding; the goal is to find the level that works best for each person with the least amount of side effects. Once the device is turned on, the VNS will deliver the stimulation without the teenager having to do anything. Typically, the VNS is programmed to deliver stimulation for 30 seconds every 5 minutes, but it can also be set to turn on for shorter periods more frequently.

What side effects may be seen with VNS Therapy?

Some risks may be associated with the surgical procedure, including the risk of anesthesia. Possible infection at the incision site is the most common surgical risk, followed by a low risk of vocal cord paralysis. The latter may occur if a nerve to the vocal cords is affected during the implantation procedure, causing the left vocal cord not to work properly. This may result in a temporary hoarseness, a very soft tone of voice, or swallowing difficulties. This problem occurs rarely and usually resolves over time.

People may experience different sensations or side effects when the

stimulation is occurring. Most commonly, people may report a temporary change in their voice, a cough or a gagging feeling, a tightness or uncomfortable feeling in the throat, or a feeling of breathlessness or difficulty catching their breath. These symptoms usually go away or lessen over time as the person gets used to the stimulation. If they are bothersome or don't go away, the stimulation settings can be adjusted. Other side effects have been reported and may vary from one person to the next. For example, people with a sleep disorder, called sleep apnea, may have more problems with VNS during the night or when high settings of stimulation are used. People considering VNS Therapy should talk to their doctor about all possible side effects and whether this treatment may be right for them.

How well does VNS work?

VNS Therapy rarely controls seizures completely when added to seizure medicines, and it may not start to work right away. For example, in long-term studies, about one-quarter of the people who have VNS treatment may have a 50 percent improvement in the number of seizures in the first three months. However, about 40 percent may have a significant improvement one to two years later. Some studies suggest that further improvement may occur after three years. Even though few people become seizure-free, improved seizure control and ability to stop or lessen the severity of seizures can be very helpful to some people. It appears to be very helpful for children with Lennox Gastaut syndrome, a form of epilepsy that is very difficult to control with medications.

Can VNS be used as part of seizure first aid?

The VNS can also be programmed to deliver bursts of stimulation when a hand-held magnet is swiped over the generator. This allows people to activate the device if they feel a seizure coming on or during a seizure. Some people have found that using the magnet may help stop a seizure from occurring, shorten it, or make it less severe. Taping the magnet directly over the generator can also temporarily stop the device. This is usually done if stimulation side effects are bothersome.

After surgery, patients are given hand held magnets that can be worn on their wrist, on the waist, or kept in a pocket. Everyone who can recognize the onset of a seizure should be taught how to swipe the magnet across the device. Other people, such as teachers or other school personnel, who may see a seizure can be taught how to use the magnet as well. Teens and their families should make sure that use of the VNS during seizure first aid is a part of their seizure action plan.

What are the practical issues to consider?

Teenagers considering vagus nerve stimulation need to be aware of all potential safety concerns associated with implanted devices and magnets. Magnets can interfere with credit cards, bankcards, computers, or other electronic items; thus, people are advised not to place their magnet next to these items. Similar to people with heart pacemakers, people with a VNS should not go into places or have procedures that could potentially interfere with electrical stimulation. Magnetic resonance imaging scans (MRI scans) of the body are not recommended because the leads may become overheated and dam-

age the vagus nerve. Although MRIs of the head can be done, only certain MRI machines should be used, and the VNS device is turned off before the scan. Other procedures, such as diathermy or therapeutic ultrasound, are also not recommended; thus, people with a VNS should talk to their doctor before having any procedures, therapies, or surgery.

VNS generators have a battery that may last five to eight years, or longer. The batteries in the newer model may last up to ten to twelve years, depending on the stimulation settings used. Regular office visits are needed to monitor the battery life. When it is time to replace the battery, surgery is done to remove the old generator and place a new one.

THE KETOGENIC DIET

What is the ketogenic diet and how does it work?

The ketogenic diet is one of the oldest treatments for epilepsy. The diet is high in fat, adequate in protein, and low in carbohydrates and is designed to keep the body in a state of "ketosis." This diet has been shown to stop seizures in about one-third of pre-adolescents. It is important to realize that this is a treatment and not merely a change in the way someone eats. The diet must be started in the hospital under the supervision of a trained dietician and medical team. Dietary requirements are carefully calculated, most of which are obtained from heavy cream or medium chain triglyceride (MCT) oil. Besides limiting the kind of foods that can be eaten, the diet also restricts calories and fluids to specific amounts. Thus, supplemental vitamins and minerals and careful follow-up are necessary.

Dieticians teach parents and teens how to create menus that are consistent with the dietary guidelines. The family must invest in a scale to weigh all foods. Everything the child ingests must be taken into consideration and calculated into the diet including medication, toothpaste, and snacks. The diet must be continued even for special occasions such as birthday parties and holidays. This level of dedication demands commitment from the entire family and school. The diet is usually started in younger children but can be initiated in teens. However, teens may find it difficult to follow since they already have certain food preferences and may have more irregular eating patterns.

Who should be considered?

Any child whose seizures have failed to adequately respond to multiple medications or who has intolerable side effects from medicines should be considered for the diet. Prior to the diet, tests are done to determine if it is medically safe for the child. For example, some metabolic disorders or other medical conditions could be aggravated by the diet. The diet should not be started if there is a concern about aspiration. If a child has swallowing difficulties and the family wants to try the diet, a feeding tube into the stomach may be placed in some children.

Close follow-up with the physician and nutritionist is needed, particularly in the early stages of the diet. Blood tests and heart function are checked, and children are monitored for too much weight loss or lack of growth. The diet may be adjusted if the child is continuing to have seizures. Like the VNS, the diet often needs to be "tweaked" in order to determine the right ratio of fats to non-fats for the individual child.

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How well does it work?

Some children who become seizure-free on the diet may be able to stop seizure medications, with advice and careful monitoring from their doctor. The diet is usually continued for about three years, although treatment may be longer if the diet is well tolerated. Some children whose seizures responded well to the diet will continue to do well once the diet has been stopped. Unfortunately, seizures may also recur in other children when they come off the diet.

What are the practical issues to consider?

The ketogenic diet is not for everyone. Some children, especially teens, can just not adhere to such a strict way of eating. Some families are unable to commit to such an undertaking. For children with multiple disabilities, eating may be a true pleasure for them and parents may not want to take that pleasure away. It's important for families and teens to talk about their expectations and whether they can realistically carry out the diet with their health care team. School personnel will need to become involved as well to make sure that the diet can be continued uninterrupted in the school setting.

A LOOK INTO THE FUTURE

There are currently two other dietary treatments being used in epilepsy. One is a modified Atkins diet and the other is a low

glycemic index diet. Although some good results have been reported, there is still too little experience to know if these diets may help seizures long-term. If these prove helpful, they may offer dietary approaches that are easier to use and have fewer side effects than the ketogenic diet. People may also read about special diets or alternative treatments on the Internet, many of which have not been tested in controlled settings in people with seizures. Parents and teens should talk about dietary approaches with their doctors and carefully consider the facts before trying them.

New ways of stimulating the brain are also being tested in an effort to deliver stimulation to specific regions of the brain. Some devices are trying to predict when a seizure may occur and deliver stimulation to stop the seizure before it even begins. Although these approaches are still being tested and are not yet available to most people, they bring new hope for people whose seizures do not respond to medical treatment.

Summary

Just like medicines, devices and diet are not for everyone but may offer unique advantages for some people with seizures. The ketogenic diet and vagus nerve stimulator are two approaches that may help teens whose seizures don't respond to medicines. Since these approaches are different than medicines, parents and their teens must have a thorough understanding of how to use them most effectively and build them into their daily life. •