the People's Doctor

A MEDICAL NEWSLETTER FOR CONSUMERS
by Robert S. Mendelsohn, MD

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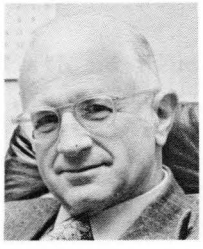
Seizures and Anticonvulsant Drugs



Dr. Robert Mendelsohn

According to Stedman's Medical Dictionary, epilepsy is "A chronic nervous disorder, characterized by attacks of unconsciousness or convulsions or both, and sometimes associated in the later stages with mental disturbances." Next comes a list of 38 types of epilepsy--from "abortive" through "visceral." Such an orderly list might lead one to believe that much is known about this condition, but as with so much of medicine, the verbiage only serves to conceal the fact that, indeed, doctors know very little about epilepsy. The ancients trembled in fear of epilepsy and offered sacrifices to placate the gods who brought on the convulsions. We moderns also tremble in fear, and we offer pills as the treatment for that which we do not yet understand. And with our "modern" treatments, we raise more questions than we can answer. If a child has fever-induced convulsions, should he be treated with phenobarbital? If so, for how long? Will the side effects of the medication be worse than another convulsion? Will anticonvulsive drugs retard brain growth in children? Does the anticonvulsant Dilantin cause birth defects? What happens if you mix Dilantin and alcohol? In this month's Newsletter, I attempt to answer these and other questions about seizures.

I urge you to pay particular attention to Marian Tompson's column (page 8) in which she presents valuable documentation on 1) the possibility of brain damage from anticonvulsants and 2) the possibility that anticonvulsants may themselves cause convulsions. Edward LeWinn, M.D., of the Institute for the Achievement of Human Potential has had a high degree of success in discontinuing anticonvulsants in his patients, most of whom suffer from brain damage. Thus, while the subject of epilepsy still is shrouded in mystery, the outcomes of these patients provides a realistic basis for optimism.

Q My 3-year-old son has been taking phenobarbital twice daily since he was 17 months old to prevent fever-induced convulsions that resulted from several ear infections. Could this medication cause any problems of its own? At what age will he outgrow his need for the medication?--S.G.

Phenobarbital for 3-year-old with convulsions

A Before I answer your specific inquiry, let me tell you that your letter questions one of the most fundamental concepts in modern pediatrics. Along with practically every other doctor, I was trained to prescribe phenobarbital for a child who had febrile (fever-induced) convulsions to prevent future convulsions.

But I began to develop doubts about this procedure when I saw that some patients had repeat convulsions even while on the phenobarbital.

And some mothers began to report to me that the phenobarbital stimulated their children instead of quieting them.

Now I'm becoming more and more convinced that it is the disease itself that produces after-effects, such as brain damage, and not the convulsions per se. While we are all terrified at the thought of a convulsion, I know of no convincing medical evidence that a convulsion itself causes damage in later life. Convulsions due to meningitis are extremely serious, while those caused by roseola are quite innocuous. While not all doctors agree with this assessment, it must enter into the determination of the relative risks and benefits of medication.

Now to answer your questions. First, yes, the medication could cause problems of its own. Some of the side effects include nausea, vomiting, hiccups, headache, drowsiness, dizziness, irritability and hyperkinetic excitement. As for the long-term effects, I'd very much like to see a 20-year follow-up study on adults who had taken phenobarbital for long periods of time as children.

We are seeing follow-up studies now on the chronic use of other drugs such as birth control pills, tranquilizers and Ritalin. The frightening information that's come out of those studies makes me very leery of the chronic use of any medication for which we do not have real life-or-death indications.

As for the age at which phenobarbital should be discontinued, some doctors encourage its use for two years, others for four, and still others until adolescence or even longer. None of these "magic numbers" has any scientific validation.

In an article entitled "Maintenance of Drug Therapy" in the April 1979 issue of Pediatric Annals (an issue devoted exclusively to the medical treatment of epilepsy), Dr. Samuel Livingston and his colleagues write, "Some patients may be better off leading a more normal life between occasional seizures than they would if they lived seizure-free in a perpetual state of drug-induced drowsiness and confusion..."

And, in the October 1975 issue of Pediatric News, we doctors were told by Dr. Karin B. Nelson of the George Washington University of Medicine and the National Institutes of Health, "There is no consensus on the long-term management of febrile seizures." Dr. Nelson further stated that prophylactic phenobarbital therapy has not been definitely proven to prevent recurrence of febrile seizures in childhood. And she pointed out that seizures have yet to be associated with learning or behavior problems.

If the long-term use of this drug disturbs you, ask your doctor to show you written scientific evidence which supports his verbal claims.

My wife and I are the parents of a beautiful 6-month-old boy. When he was 10 days old, our son was diagnosed as having severe bacterial meningitis (cerebral). He remained in critical condition for approximately four weeks, and it was thought several times during this ordeal that he would not live. When the baby finally recovered, the attending physician prescribed phenobarbital elixir at the rate of three teaspoons a day. Three weeks ago, the doctor prescribed Clonopin.

At his present age of six months, our baby is unable to turn over, and he is not very alert or responsive to auditory or visual stimulation. He is, however, experiencing normal physical growth. We are afraid that the medication has so sedated him that his ability to relate to, react to and learn from his environment is being adversely affected.

The doctor has told us that his mental aptitude can't be determined until he's six years old. We feel that a child's mentality is developed and maintained from birth to six years and is, in great part, based on outside influences. How then can we expect this baby to gain in aptitude and physical strength when he is constantly under sedation? Do you concur with his current treatment?--G.M.

Phenobarbital and Clonopin

A

While I am deeply touched by your problem, I cannot diagnose or treat individual cases by mail. I can, however, offer some general comments that may apply to your child.

My answer to the previous question pretty well sums up my feelings on phenobarbital. With regard to the anti-convulsant drug Clonopin, the manufacturer, Roche Laboratories, warns: "Because of the possibility that adverse effects on physical or mental development could become apparent only after many years, a benefit-risk consideration of the long-term use of Clonopin is important in pediatric patients."

The Physicians' Desk Reference says that the medication produces depression of the central nervous system (CNS); other adverse effects include drowsiness in 50 per cent of patients, and ataxia (inability to coordinate muscle movement) in 30 per cent. Furthermore, behavior problems have been noted in approximately 25 per cent of patients.

Symptoms of Clonopin overdose, like those produced by other CNS depressants, include somnolence, confusion, coma, and diminished reflexes. Finally, the CNS depressant action of this class of drugs is increased when barbiturates such as phenobarbital are used at the same time.

Your concern about your child's development under the influence of these medications is certainly justified. I hope this information will help you ask your doctor the right questions as he tries to justify his prescriptions.

Is your doctor prescribing phenobarbital to prevent convulsions? Then you should know that according to research being conducted at Ohio State University, phenobarbital, which is often used to prevent possible brain damage from epileptic seizures, may itself threaten brain growth. Sarah Tjioe, assistant professor of pharmacology at Ohio State's College of Medicine, reports a reduction in the size of the brains of baby rats which were given phenobarbital.

Q

I am a 32-year-old woman who has controllable epilepsy, and I have been seizure-free for more than four years. I have been taking phenobarbital and Dilantin. During the past year and a half, I have suffered three consecutive miscarriages. None of these pregnancies lasted longer than two and a half months, but my doctor can find no explanation.

I already have two healthy children, but I was only on phenobarbital during the time I was pregnant with them. Can you tell me whether Dilantin, or Dilantin and phenobarbital combined, could cause a woman to miscarry?--Mrs. D.B.

Dilantin and birth defects

A

I have no information that would link your miscarriages to Dilantin. But I do know that recent reports suggest a relationship between use of a number of anticonvulsant drugs, including Dilantin, and birth defects in infants born to mothers treated with such drugs. There is not only an increased risk of cleft lip and palate, but also a collection of defects named the "fetal hydantoin (Dilantin) syndrome," which includes

defects of the skull, face, nails and fingers, prenatal growth deficiency, and mental retardation. Furthermore, there are recent reports of neuroblastoma (type of malignant tumor) in two children with this syndrome. A further report in the July 25, 1977 issue of the Journal of the American Medical Association described another kind of malignant tumor in an 18-year-old patient with cleft lip and palate, whose mother had taken Dilantin during pregnancy.

Dilantin, like DES, thus may have the chemical ability to produce immediate congenital defects as well as later cancer in children born to mothers who took these drugs.

Whether or not later research links Dilantin with miscarriages, the broader question to raise with your doctor is whether you should be taking anticonvulsants, as well as any other drugs, if you wish to become pregnant.

Dilantin and alcohol

Has your doctor prescribed Dilantin to control convulsions? If so, you should know that, in the presence of heavy drinking, a larger than normal dose is required to maintain the therapeutic effect. If you have a history of alcoholism, even though you are now an abstainer, you may need different doses than those required by non-drinkers if you are taking isoniazid (for tuberculosis), tolbutamide (for diabetes), or Dilantin.

Q My husband has been afflicted with epilepsy since he was seven years old. His doctor has him taking one Dilantin, three Dilantin and phenobarbital combined, and one Tegretol daily. My husband still suffers an occasional seizure. He tells me his doctor has told him it's all right if he socially has a couple of drinks of an alcoholic beverage, provided he keeps the drinking to a minimum. In view of all the medication my husband takes, it's hard for me to believe this is true. What is your opinion on combining these drugs with alcohol?--Worried Wife

A Alcohol strengthens the action of phenobarbital, and the combination is potentially lethal. And alcohol may inhibit the anticonvulsant action of Dilantin. Tegretol may strengthen the sedative effect of alcohol. The combination of alcohol and a tricyclic antidepressant (to which Tegretol is chemically related) has been fatal. That is what the medical books say. I wonder whether there has been some distortion in the third-hand information that has traveled from your husband's doctor to your husband to you.

Q What are the toxic after-effects of Dilantin and Decadron? Our 45-year-old son was given these drugs intravenously for 12 days and now is paralyzed in his hands and arms and has no coordination in his leg muscles. We were told this paralysis could be the result of an overdose of this medication. This happened about two months ago, and he is still partially paralyzed.

His mind is clear, and he was given these drugs because he developed convulsions following a brain scan. The brain scan was taken because he had a cancer removed four years ago, possibly a melanoma. He never had any headaches, nor does he now. What is your advice?--Tucson Readers

Dilantin and Decadron

A Dilantin (an anticonvulsant) and Decadron (an adrenocortical steroid hormone) both are powerful drugs with plenty of important adverse reactions. While Decadron can cause convulsions and muscle weakness, paralysis is not one of its listed side effects. Having said this, let me emphasize that brain tumors, particularly melanomas, are extremely serious conditions, and if medicine has any value at all, serious diseases merit strong medicine.

To reject the use of powerful, though dangerous, drugs in the treatment of life-threatening conditions borders on nihilism and would deprive us of some of the most brilliant achievements of modern medicine. Thus, penicillin is truly miraculous in overcoming certain kinds of meningitis, but is risky when used for the common cold. Cortisone is life-saving in cases of Addison's disease, but represents dangerous overkill when used to treat sunburn.

In your son's case, there is no satisfactory treatment for melanoma, and, therefore, the patient, given full opportunity for informed consent, has the right to accept treatment with even the most hazardous chemicals. While I am often concerned with the tendency of modern medicine to apply extreme measures to mild diseases, this is hardly the situation with your son.

Q For the past 15 years our son has been taking medication to control epileptic seizures; he takes Mesantoin and phenobarbital daily. I know this has caused personality changes, and I've also heard that phenobarbital can build up in the body. Is this true? It's surprising how few doctors concern themselves with this problem.--N.P.

Long-term use of anticonvulsants

A You don't tell me how often your son has seizures or when the last one occurred, but I do know that 15 years is a long time to be taking two such powerful medications. Phenobarbital can lead to both psychological and physical dependence, and Mesantoin should be used only after safer anticonvulsants have been given an adequate trial and have failed.

Some time ago, I wrote about the lack of long-term, good scientific studies on the chronic use of anticonvulsants. To my knowledge, the storehouse of information on this subject has not grown, but public concern over long-term use of medication has increased dramatically.

In my opinion, your next step is to read carefully the prescribing information that your druggist has available on both these drugs and then sit down with your doctor for what seems to be a long overdue discussion.

Valproic acid

Leafing through the medical journals, my eye fell on the multi-page advertisement for Depakene, Abbott's trade name for valproic acid. And, as is my wont, my eye went first, probably to the frustration of the advertising agencies which dream up these ads, to the small print on page three.

I have watched valproic acid for some time because of the controversy this drug has generated. Because the drug has been available in Europe for more than 12 years, some have claimed that the time lag in introducing this anti-epileptic to the United States was too long. Others have pointed to the thalidomide episode as an example of the value of caution on the part of the government agencies. One Ph.D. pharmacologist felt so strongly about valproate that he traveled to Mexico to bring back valproate for his epileptic son.

In 1978, the FDA gave its blessing to Depakene, and Abbott's

marketing capability went into high gear.

Returning to the ad in the medical journal, the small print contains dozens of lines of contraindications, warnings, precautions, interactions, and adverse reactions (gastro-intestinal, central nervous system, dermatologic, psychiatric, musculoskeletal, blood, and liver). In the Journal of the American Medical Association (November 10, 1978), the Department of Drugs reports the overall incidence of adverse reactions in pre-marketing clinical tests was about 20 per cent. Of particular interest to me as a pediatrician are the reports that children appear to be particularly susceptible to the development of prolonged bleeding time, that some children who took the medication manifested aggressiveness and hyperactivity, and that laboratory studies revealed major skeletal and other developmental abnormalities in the offspring of pregnant test animals.

If your doctor suggests taking Depakene, you should first carefully compare the prescribing information of valproic acid with that describing the drugs you are presently taking. Even more basic is the need for continuing skepticism about the modern drug management of epilepsy. In the Journal of the American Medical Association (March 6, 1978), an article on epilepsy begins, "The history of treatment for epilepsy and cerebral palsy has been one of optimistic claims and discouraging results." J. Kiffen Penry, M.D., head of the section of epilepsy research of the National Institute of Neurological and Communicable Diseases and Stroke has said that, in epilepsy, the belief was widely held for some time that drug management could control seizures in 70 to 80 per cent of patients, but this "commonly accepted fact" was based not on well-controlled trials, but on "biased studies without good control."

While it is somewhat reassuring to know that Europeans have experimented with valproate for these several years, I am still ethnocentric enough to repeat for American users the tongue-in-cheek maxim in regard to any new drug, "Hurry up and use it before its full side effects are identified."

Q Since 1948, I have been taking the anti-epileptic Mesantoin and have done very well on it. How compatible would this drug be with three tablets of Triavil three times a day? Should I expect disagreeable effects?

My present doctor knows nothing of the Mesantoin, and I have no intention of telling him. He has prescribed Triavil temporarily to relieve tension due to my present home life.

Please don't tell me to tell my doctor about Mesantoin--even my husband of 17 years doesn't know about it. If he did know, he would blow it out of all proportion, as would most doctors. We are still in the Stone Age.

All my adult life, I have held very responsible positions and have been very active. I never asked the neurologist who originally prescribed my medication 30 years ago to clearly spell out a diagnosis, but I had my suspicions. Over the years, I have seen that neurologist very little and then only because of laws relating to continuing the prescriptions. The last time I saw him, he told me it was too bad I had to waste my money coming to see him just because of absurd new laws regarding Mesantoin. Please give me your advice.--Anonymous

A *Secret seizures*

You are plenty smart to be suspicious of the compatibility of the anti-convulsant Mesantoin (prescribed for seizures) with the antidepressant Triavil, since the particular class of antidepressants that includes Triavil may necessitate changing the dose of Mesantoin.

I will respect your decision to keep your secret from both your hus-

band and your doctor, even though I presume that over the past 30 years you have carefully read and reread the prescribing information on Mesantoin which in bold letters contains the statement: "The patient must be kept under close medical supervision at all times since serious adverse reactions may emerge."

Every patient on anticonvulsant medication must face the problem of secrecy versus disclosure. I certainly respect the opinions of those who claim that, with modern treatment, epilepsy has emerged from the Dark Ages and can be discussed freely. On the other hand, on the basis of my clinical experience, I also respect the opinions of those like you who remain convinced that secrecy is the best policy. But your secrecy carries with it the definite responsibility to independently learn at least as much about your condition and your medication as others learn from their doctors.

Another View (cont'd from page 8)

7) The physiological key to the prevention or control of seizures is the attainment of the highest possible level of cerebral cortical function in its relation with the cerebellum and the reticular system. By their action in interfering with such an attainment, anticonvulsant drugs negate this fundamental conceptual principle."

Seizures, the complete text of these thought-provoking papers by Drs. Fay and LeWinn, is available for $1.50 from the Bookstore of IAHP, 8801 Stenton Ave., Philadelphia, Pa. 19118.

Back issues of *The People's Doctor Newsletter* are available at $2.00 an issue from:
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Dr. Mendelsohn's book, "Confessions of a Medical Heretic," is now available in paperback (Warner Books, $2.75).

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Another View

by Marian Tompson
President, La Leche League International

Martin was 19 years old when he had his first seizure. Although tests revealed no cause for the convulsion, he was put on Dilantin and phenobarbital for three months. A year later he had another seizure, and his doctor suggested he take the medication for the rest of his life. ("Why take a chance?")

As the years passed, Martin's mother became concerned about the way the drugs were affecting her son. Although Martin ate well and worked out regularly, his face had a "worn look." Six years later, influenced by his mother, Martin decided to gradually reduce his medication until he was completely off it. That was two years ago, and he has been seizure-free ever since.

At the opposite pole to my young friend, Martin, stands my father-in-law who had occasional convulsions for more than 10 years and who never took any medication! As a young married man who was raising a family during the Depression, he wouldn't even consider spending money for doctoring. Eventually, the seizures simply stopped.

Obviously, every person who has convulsions does not take anticonvulsant drugs. Yet almost everything written on this problem is based on the observations of people who have been treated with the standard drugs. So I was intrigued when I came across papers written by two physicians, Temple Fay and Edward LeWinn, in the Reports of the Institutes for the Achievement of Human Potential which explained why anticonvulsants actually multiply the problems instead of eliminating them.

In his article, "The Other Side of a Fit," Dr. Fay proposes that epilepsy is not a disease but is instead a symptom of brain injury which occurs in the absence of sufficient oxygen, as is often the case in the presence of profound physiological changes in the brain's environment. He further suggests that seizures are produced through a mechanism provided by nature to protect the person, precisely in the same way that vomiting restores a state of normality. Building on this theory, Dr. LeWinn in his paper, "A Bill of Particulars on Seizures and on Discontinuing Anticonvulsant Drugs," proposes that seizures are the ultimate product of loss of cortical control of lower brain levels and that this loss of control is intensified by the consciousness-reducing effects of the anticonvulsant drugs now in use. The answer would lie first in removing drugs which reduce cortical control and then in restoring and strengthening cortical control by a program which permits central nervous system maturation and enhances brain development.

Anticonvulsant drugs actually work only for a fraction of people. An editorial in Epilepsia (17:xiii-xv, 1976), a medical journal devoted to articles on seizures, revealed that "seizure control is achieved for two years in 30 to 37 per cent of patients, but this figure falls to approximately 20 per cent at five years and 10 per cent at 10 years." Furthermore, "Some patients suffer more from chronic toxicity--due to anticonvulsants--than from their seizure disorder, and the modern management of epilepsy requires constant vigilance to strike a balance between the burdens of the disease and the complications of therapy." According to Dr. LeWinn, seizure activity is accompanied by a large increase in blood flow in the area of injury where the seizure focus exists, a process that may be regarded as part of the reflex defensive mechanism postulated by Dr. Fay. LeWinn asserts, "It would be paradoxical and indeed absurd if the brain, in response to a situation of need or distress, caused itself further injury." He concluded, "Experience with modern anticonvulsant drugs over the 40 years since their introduction shows that:

1) Their use is not based on sound physiological rationale.

2) Their use in children causes intellectual dulling and stupefaction, often sufficient to interfere seriously with developmental processes already impaired by brain injury, among them those which normally lead to control of reflex seizure mechanisms.

3) Their use is often accompanied by many other undesirable side effects, some developing insidiously but nonetheless capable of serious impact on health.

4) Their effectiveness in controlling seizures, which is the only purpose for their use, is at best highly questionable.

5) Their present-day continuing use ignores the newer knowledge of neurophysiological mechanisms and of the effects of maturation and development on these mechanisms.

6) Their toxic or fatiguing actions on the cerebellum, combined with their depressing effects on the cerebral cortex, often tend to release seizure mechanisms with the result that, instead of suppressing seizures, these drugs may encourage their occurrence.

(cont'd on page 7)