

Diagnosis of Epileptic and Non-epileptic Spells
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Introduction

Andrew:

Hello and thank you for joining us once again. I'm Andrew Schorr broadcasting from Seattle, where I live. We go worldwide. Northwestern Memorial sponsors this and what a great public service. We do this every two weeks, and each time we connect you with a leading medical expert. We talk about a significant health condition. And today we're going to talk about seizures and spells, epilepsy, as part of it but also nonepileptic spells too. You know, in the greater Chicagoland area there are an estimated 80,000 patients with epilepsy, and we're going to understand what seizures are.

Now, I'm going to tell you where I'm coming from not being diagnosed with epilepsy. In two of my three children, it was a terrifying experience where as little babies they would have colds and then their fever shot up. And I would be holding one of my little kids and their eyes would roll back in their heads and they'd be rigid and it seemed like it went on forever, probably just a few seconds. That was a febrile seizure, and it happened to one of my kids twice and another kid once. Very frightening. They weren't aware of what happened. They're fine. They've gone on with their lives. They're doing well, but what was that? So that's one personal experience. You may have had others. They're not that uncommon, but when they happen in a recurring way, well that's more of a concern.

Well, I want you to meet Richard Newman from Skokie, Illinois. Richard is 63. For more than 40 years he's been dealing with seizures. Richard, welcome to the program. When you have seizures over time what are they like? What happens to you?

Richard:

Well, that's varied over the years. When I first got it, 1964, it would occur where I would have a hallucination. Then I would go wandering around doing things. It was called at that time psychomotor seizures. Now because of the medication I have something a lot softer than that where I can't speak, can't read, can't talk to somebody and get very confused about what I'm doing.

Andrew:

Right. I was just going to say you're married, you have kids, you have grandkids.

Richard:

Oh, yeah.

Andrew:

So you have people around you. Are there times when this has happened to you for maybe just a few seconds, you're not even aware of it? Somebody says, Hey, are you okay? Hey, were you away somewhere in your brain for a minute?

Richard:

Yes, does happen.

Andrew:

Well, when this all started, and I know you were just like in your 20s or 20 years old, must have been scary, where you felt you weren't in control.

Living with Epilepsy

Richard:

It was a little bit scary, not that much probably because I was just 20. And I had a lot of support then from my friends and my family.

Andrew:

Well, I'm glad it's gone on, and you've gone on with your career. I know you're a computer systems guy working in Chicago, and you've done well. I know you don't drive though, right?

Richard:

Right.

Andrew:

And that's because of what concern?

Richard:

That's because when I have one of these seizures I lose what I call process ability. That is if I'm in a car, driving it, not being able to speak isn't much of a problem, not being able to read can be a problem because I can't read road signs, but even if I could I had a seizure I would not know how to use a brake pedal.

Andrew:

Whoa. That would be a concern. Now, let's talk about what's happened to you in recent times. You've taken medicine over the years, and then you had one of these video EEG workups, right?

Richard:

Yes.

Andrew:

Not that long ago, early in the summer, I think, in May.

Richard:

May.

Surgery for Seizures

Andrew:

And we'll learn what that is. And then you actually had a surgery on part of your brain to try to target an area that maybe was responsible for the seizures or one of the bad actors, right?

Richard:

Right.

Andrew:

How has that worked out? When you had this procedure at Northwestern Memorial, what, I know you keep records about all this and you've tracked it for a long time. How are you doing now?

Richard:

I have not had a seizure of any kind since that operation.

Andrew:

Is that a record for you?

Richard:

No, that's not a record. That hasn't happened for several years. We're going to have to get to about ten months before as far as I know it has never happened.

Andrew:

But it's reversing the trend, right? Because you had been getting worse.

Richard:

Well, right. Recently, if you go back ten years or so, I don't--it could get to like eight months, six to eight months I've had them. And in the last year it's simply been climbing up faster and faster over that time.

Andrew:

And we're talking now almost six months, certainly great news. Well, great for you.

Well, let's meet your doctor. And I want to make a point as we do and that is--we talked about 80,000 or so people in the greater Chicagoland area dealing with

epilepsy. We're also going to learn about nonepileptic seizures or spells as well. Not every doctor is a specialist in this, but with us tonight is one who is and that's Dr. Stephen Schuele.

Dr. Schuele is director of the Northwestern University Comprehensive Epilepsy Center at Northwestern Memorial Hospital. Dr. Schuele, welcome. And I know it must make you feel good to know that you have intervention with your patient Richard and he's on a much better track than he had been of late.

Dr. Schuele:

Good evening Andrew, and thanks for having me on your show. Yes, I think it's good to hear from Richard how he has been doing since the surgery. I do think that it is something I had predicted, and I think we were very confident that this would most likely happen, but like everything in medicine there's no hundred percent. I think that when he came we predicted his chance of being seizure free maybe between 70 and 80 percent, a little bit less because he came so late. But knowing that it happened and that it happened for six months I think is very reassuring. And I think the one who should be the proudest of this is I think Richard himself who had the courage after all these years to take the step.

Andrew:

Right. And one of the things we'll talk about, and I know you agree, Richard, you and I have talked about it on the phone, is how when somebody has an ongoing condition like this you need to connect with the best care and people who are most knowledgeable. And certainly the knowledge about epilepsy and nonepileptic seizures has been grown growing, and that's what Dr. Schuele and his team specialize in. So it's a great connection between a patient and the best quality care you can get.

Dr. Schuele, help us understand what's a seizure, what's a spell, when is it epilepsy, when is it something else. Help orient us in all that.

What is a Seizure? Who gets them?

Dr. Schuele:

I'm using the term "seizures" relatively broad because I'm getting patients sent with all sorts of if you want to call it fits or spells or seizures. And part of my task is to figure out what of these seizures is epileptic and which one of these seizures is not epileptic.

Epileptic seizures is a sudden phenomenon of an electrical shortcut in your brain causing basically your brain waves going haywire and nonfunctioning and either in the whole brain or in a particular part of the brain. So that's why some patients only have symptoms from that particular part and others pass out completely, and if the discharge gets very strong then they start convulsing.

On the other hand there are sudden spells or seizures that grab us or “seize” us which are not epileptic. They are caused by a sudden lack of oxygen to our brain or a sudden lack of blood supply to our brain or a sudden intoxication or they can be stress related. They can be provoked by panic attacks or they can be just an expression of the human body of some inner psychologic stress going on.

Andrew:

Well, it was really scary, as I talked about that story of my small children. My understanding is with a spike in fever with a young brain you can have that shutdown or whatever, febrile seizure. So is that epilepsy?

Dr. Schuele:

No, that is not epilepsy. I think we share with our patients that we all have the ability to have epileptic seizures. I'm trying to point that out to many of my patients, that our brain runs on electricity and if the electricity has a shortcut we can have a seizure, an epileptic seizure. The difference is the trigger it takes for someone with epilepsy to have a seizure and the trigger it takes for someone who doesn't have epilepsy to have a seizure.

And we only call epilepsy if you're brain produces epileptic seizures without any outside trigger, reliably repetitive trigger, if your brain has a seizure out of the blue. Sometimes they can be related to stressful times. They can be brought on more frequently by sleep deprivation or they can be produced perimenstrual. But the brain is a little bit hyperexcitable in either a part or the whole brain and that leads to unprovoked seizures, and that's what we call epilepsy.

On the other hand, every human brain goes through phases where it is more vulnerable to have what we call provoked seizures, meaning small children in a certain time of the ripening of their brain have a phase where they are particularly susceptible to high temperature and fever and in that time they can have seizures. Most of them will outgrow this phase and they will never have seizures again in their life. This problem is also not directed towards the brain, so you're usually not trying to treat the epileptic brain, you're trying to treat the fever. Because if you control the fever you don't have seizures.

Another example is that many of us--we have many patients who have epilepsy, actually have a single seizure in their life in some vulnerable phase, sometimes in the college years when they don't sleep a lot or maybe they drank a little bit too much. They can have a single seizure and once their life is a little more regulated they will never have that again. Is it fair to call it epilepsy? We usually tend not to call it epilepsy because we think if you call it a disease you usually also tend to try to treat it and why would you want to treat something that's never, ever going to

happen again? So we restrict the term epilepsy not only to seizures that are unprovoked but also to conditions which are recurrent. So you need at least two seizures in your life in order to call it epilepsy.

Restrictions for Epilepsy

Andrew:

Okay. Well, there's a lot to talk about. Just a quick question then. Typically when people have recurrent seizures then they're people who then stop driving. That's what Richard was describing. So is that wise then, when somebody is in fact diagnosed with epilepsy that it's to that point then when you have to be careful about using equipment, if you will?

Dr. Schuele:

That is actually different, I think. I think that you don't have to have epilepsy in order to be careful not to drive or take some other precautions. And I think that's a good opportunity to talk about why do we have these driving restrictions, and are they arbitrary or are they a punishment for epilepsy patients or patients with seizures or why do we choose certain durations.

I think historically it has been different. The driving restrictions for patients with epilepsy were much harder than for patients who had a heart attack and passed out and shouldn't obviously have been driving by the time they had the heart attack, and the cardiologist wouldn't restrict their driving for any length of time or maybe for a couple of months while they recover. Whereas patients with epilepsy would be restricted from driving for several years.

I think that has changed. I think we are trying to be more aware of what is the actually risk of if you had one, one spell which makes you incapacitated out of the blue and unexplained, what is the risk of having that spell again while you're driving. In patients with a single seizure that risk is usually the highest within the first three to six months after that single seizure. Afterwards you can easily end up in that group of people I just mentioned who never have a seizure again. So I think that's the rationale of limiting driving restrictions after a single seizure to six months.

Andrew:

We're going to take a break, Doctor, and when we come back we're going to begin to understand when someone actually has a diagnosis, these recurrent seizures, how you kind of understand what you're dealing with. I know you have lots of diagnostic workups you can do now at Northwestern. You'll help us understand that. You did that with Richard, which eventually led to a surgery we'd like to hear about, but we'd like to understand the way you diagnose it and figure out what are you dealing with and how you come up with a plan of what to do about it.

We'll be back with more of Patient Power as we discuss seizures and spells, epilepsy. It's all coming up as we continue on Patient Power sponsored by Northwestern Memorial Hospital.

Diagnosing Epilepsy

Andrew:

Welcome back to Patient Power on healthnet.nmh.org. We're discussing epilepsy and understanding that and nonepileptic spells as well. We have a leading expert from Northwestern, Dr. Stephen Schuele. He's the director of the Northwestern University Comprehensive Epilepsy Center at Northwestern Memorial Hospital. He's a neurologist. We also have with us one of his patients, Richard Newman. He's been living with epilepsy for more than forty years now, but he's been living a full life and just this past summer had a surgery at Northwestern. And that seems to have made a big difference and he hasn't had a seizure in five months, which is a tremendous reversal of the trend when they were increasing.

So, Dr. Schuele, let's get more into the thick of it. So when someone ends up with a diagnosis of epilepsy, and we said there may be 80,000 people around the Chicago area who have that situation, then what do you do to try to understand what you're dealing with? What are some of the diagnostic workup you do nowadays?

Dr. Schuele:

Well, the diagnosis of epilepsy is first based on the patient's history. One of my colleagues once said that epilepsy is the greatest teacher because the seizures teach you what happens to the patient's brain during an event. So you have to be very, very careful in listening. It often tells you what type of epilepsy the patient has but it also helps you understand what impact it has on the patient's life and what risks are associated with that particular patient having these seizures.

Although I'm always trying to get a history just from my patient and I'm trying to get the part he's remembering because it's important to know when your patient is actually passing out and at what point others have to pitch in and tell the story. It is significantly easier in the time of cell phones. So one of my standard practices is if I get a new patient and he comes unaccompanied I ask him who has witnessed a couple of his seizures? Who can I call? Can they tell me what happened?

And then the diagnosis of epilepsy is based on your impression of the patient's history. Does that sound like something which could happen if there's an electrical shortcut in the brain? Can that cause these kind of phenomenon? So that depends on your judgment and experience. And then once you said, Okay, I do think this is most likely epilepsy, then you have to ask yourself the next question: What could have caused that? Was it a problem of the brain or did he have low blood sugar that day or did he drink too much or did he have some--did he take some drugs

which might have provoked that, and should you bother talking about that rather than talking about what could have gone wrong in his brain.

Andrew:

Yeah. I was just going to say you get to that point though and then you're trying to zero in on, is this, if you will, externally an unprovoked situation.

Dr. Schuele:

Exactly. And then once you've decided, yes, it has something to do with the way the brain is formed then you have to ask yourself do you think that it is something which is inherited from early on or is it something acquired. Could there be a new stroke? Could there be a brain tumor? Could there be some infection? That's usually followed by physical examination and then also by imaging studies. So you want to have an MRI of the brain. A CAT scan I think nowadays is appropriate in the emergency room setting, but for a detailed workup on epilepsy I think an MRI of the brain is the study to do to find out if there's some underlying lesion you could detect and which has to be operated just by itself because it's a tumor or it at least explains why the patient has epilepsy.

A Brain MRI

Andrew:

Okay. Hold it just one second, Doctor, I just want to ask Richard a question.

Richard, so you had an MRI. And what did it show?

Richard:

I believe it showed that I had problems in the temporal lobe of my brain, which I think was not a surprise to either the neurologist I had in the sequence, because that's where a lot of this comes from, that is, the description of what I have. But the doctor would be able to say, no, you're right or you're wrong on that, Rich.

Andrew:

Okay. Let's go on. So you do the MRI. And now you're looking at the brain. The MRI will show you a picture of something, but you're not looking at electrical activity yet.

Dr. Schuele:

No. The MRI shows me the structure of the brain, and in Richard's case it showed a small cavernous angioma. And the location of the cavernous angioma was visible on the MRI, and I would predict it wasn't visible on CAT scans he had--CT brains he had before, but I'm just postulating that.

Andrew:

What is this thing you're talking about, just define it for us. The cavernous...

Dr. Schuele:

A cavernous angioma is a small vascular malformation which is something, basically a small busted blood vessel he had inside his brain. The break of the blood vessel by itself didn't cause any consequences because it's very, very small. But the iron which we have in our blood which kind of leaves the bloodstream and kind of deposits in the brain tissue is extremely irritable to the brain and can cause some of the most irritable focal epilepsies, so epilepsies which start from a small area of the brain. And the irritation is so tremendous in that area that virtually no medication, no matter what dose and how many, is able to completely dampen it. And that's what Richard had.

Andrew:

But he tries to come up with a diagnosis. And this seems like real detective work then.

Dr. Schuele:

I can show you that with Richard. When Richard came he had hallucinations. I think he had experiences of things which weren't there, but I think it was a déjà view experience, if I remember correctly.

Richard:

Uh-huh.

Dr. Schuele:

And then he became unconscious, which is the phase where his wife pitched in and said that for a little brief period he's unresponsive and stares off and then after he clears up he has difficulty to find his words. So the detective part begins with the fact that these déjà view experiences are very, very typical for temporal lobe epilepsy, so the temporal lobes we have behind our temples on the left and right side. They also are typical for causing seizures where people don't convulse but start to stare off.

And then the interesting thing is that if you have seizures where you are unable to speak after the seizure is over that indicates that the seizure probably came from the area where you have your language, because we have our language cortex on one side of the brain. And so it is intuitive to say, you know, if you have that type of seizure and afterwards you are unable to speak probably that brain which produces language has been disturbed, at least for a little bit before it recovers.

Andrew:

Wow.

Dr. Schuele:

So just by the history you get from Richard you could probably assume with very high precision that he had all his life left temporal lobe epilepsy, and that's exactly what the MRI showed as well.

Electrical Conductivity in the Brain

Andrew:

Wow. So that confirms it. And so you have this busted blood vessel. Now, we're talking about an electrical problem. So did I hear you say that there's an iron issue too, and does that affect electrical conductivity in the brain?

Dr. Schuele:

Yes. What happened if you do a normal EEG, which is a brain wave test which had been first described in 1935, it is able to measure our brain wave activity. If you do a brain wave test on Richard you see that he has, even in his awake state before the surgery, he had sharp looking waves which stood out of his normal background coming directly from his left temporal lobe or area. So just by a regular EEG we had already some evidence that there's some abnormal electrical activity in that area, and it further supported our suspicion that he these are epileptic seizures and they're probably coming from that area.

Now, the final proof that these are epileptic seizures came when we admitted Richard to our video EEG monitoring unit, which is a specialized monitoring unit with 24-hour technology supervision with the highest standard of safety which allows us to, even in patients who only have a seizure every month or every two months, to take off their medication and in a controlled environment record some of their seizures. And if you have epilepsy even if the frequency of seizures are greatly reduced, if you take someone off medication you can with a very high percentage record a couple of seizures, even within three or four days. And that's what we did with Richard.

And when he had the seizures you could see that these sharp waves in the left temporal region we had already seen before would build up to an abnormal rhythm which would last as long as the seizures lasted and really proved that the seizures were epileptic and that they also came from that area of the brain.

Andrew:

Well, this is fascinating. What we're going to do after the break is we're going to find out how you did this surgery and what was done at Northwestern to then deal with the problem to put Richard in a much better situation. And I think, folks, I hope what you're getting out of all of this and we're pursuing Richard Newman's case study a little bit here because the man has been living with epilepsy for more than 40 years, and now he's gotten very specialized care at Northwestern, a wonderful center for epilepsy treatment, and he's doing much better.

And I think the point is here is that there are a variety of approaches, diagnostic and the art of epilepsy medicine as you're hearing from Dr. Schuele that you want to bring to bear for you so that you get the best care. So I want to hear about this surgery. What do you do nowadays to help people like Richard. This is all on Patient Power as we continue, brought to you by Northwestern Memorial hospital. It's call coming up as we continue after this.

Resective Brain Surgery

Andrew:

Welcome back to Patient Power on HealthNet on nmh.org. It's also a special edition on Health Radio and thank you for carrying it there also. We're visiting with Dr. Stephen Schuele, who is a neurologist and a specialist in epilepsy at Northwestern Memorial Hospital in Chicago. And also we're kind of taking the story of Richard Newman from Skokie as sort of a case study.

And where we left off with is Dr. Schuele and his team did detective work to really see what was going on in sort of a busted blood vessel that probably Richard has had for decades that was really causing seizures, unprovoked seizures and understand what was going on. And so that led in June then, Dr. Schuele, to surgery.

So what kind of surgery are we talking about? What did the neurosurgeons, I guess, do to try to control the problem?

Dr. Schuele:

Well, we're talking about resective brain surgery, so we are talking about identifying precisely the area in the brain where Richard's seizures come from and also determining the area around that lesion like I mentioned before. It was a small malformation of a blood vessel. We called it a cavernous angioma. So we tried to identify that area and we tried to determine how good his brain function is around that area. Because obviously if you do brain surgery you want to take out the area which causes the seizures but you also have to know what happens if you take part of the brain out. Will the patient have a stroke? Will he have some deficits which are not acceptable?

So there are two parts to the brain surgery. One is the part to identify the lesion, and the other part is to identify the function of the brain around. So that makes it a relatively comprehensive workup. So after we got the video EEG, we had Richard seen by our neuropsychologists, and they found that his cavernous angioma, which was right at the tip of his temporal lobe, was sitting in front of a brain structure which is in many patients damaged at the same time and then that makes it

obviously easier to take it out if it's already damaged, but in Richard, right behind that angioma he had a high-functioning area of his brain which is called the hippocampus.

And Richard is a highly accomplished professional and we are kind of discussing with him how big of a resection should we do to be hopeful that we got everything out and where should we stop. Because obviously the more we would have taken out the easier it would have been to stop the seizures but it also would have endangered him. So we have fortunately an experienced epilepsy surgeon at Northwestern Memorial Hospital, doctor Josh Rosenow, who is very accustomed with stereotactic microscopic brain surgery. So he has the dexterity, I think that's the most important part but also the microscope and the instrumentation to do a resection which is so precise that it takes out the angioma and leaves the important structures behind.

Andrew:

Right. Let me just ask Richard a question.

So, Richard, obviously having brain surgery is not something you take lightly. So you understood what they were going for. Have you seen any degradation of function other than the benefit of not having the seizures?

Richard:

I have not fully recovered from the surgery, which was expected because, you know, they're cutting in your brain.

Andrew:

No kidding.

Richard:

So there is a certain impact in ability for me, an ability to remember capital items, that is like a person's name and the capital of a state's name, stuff like that. But that's largely been corrected. And there was a problem to be able to remember what I'll call functional items. Like if I look at a pen can I say pen. That has largely been restored, but some of it is still there. I don't believe I have forgotten anything. It's a matter of the brain connecting properly for certain things.

Medications for Epilepsy

Andrew:

But I think it's a great reversal of the trend for sure.

So, Dr. Schuele, we're going to take some e-mail questions in a second, but the point is in some cases surgery is needed. Where are we with medications now? Because I know Richard was on a bunch of medicines for years and years and years. How are we with medicines to help control epilepsy?

Dr. Schuele:

I think we've advanced significantly with medications. I think the medications right now are probably able to control epilepsy in two-thirds of cases. So that means the mainstay of epilepsy treatment is medications.

And I think the major advantage we've made from the old times of phenobarbital and Dilantin and even older medications is that we are now able to offer medications which have a far superior side effect profile. They are not necessarily more effective, but they have a significantly better side effect profile. So in the old days I tended to joke to say you could recognize a patient with epilepsy because he either was very tired from his medications, felt like a zombie and that was one of the typical medications which was used at the time. And other medications would cause gum swelling and other things which would also be recognizable.

Nowadays we have medications patients like Richard can take and nobody except for him and his wife, because he shared that with her, would recognize that he was on medication. And I think that's extremely important.

Now, having said that, there is about a third of patients who are not controlled by medications. And for them usually after two or three medications failed you recognize that epilepsy is not going to stop by medications. It can quiescent for a little bit, it can go away for six months, but it's not going to stop. That is something we now more and more--I don't think that people would have waited nowadays 43 years before they offered Richard surgery. I think nowadays we think that if you try two or three medications and it doesn't work after a couple of years you should--your only real chance of a seizure-free life is a surgery.

Now there's obviously nothing you can offer to everybody. Only a small percentage of the patients with what we call medication-resistant epilepsy are surgical candidates, but I think it is important to pick those out and offer them a chance of a seizure-free life.

Andrew:

Right. And I think this underscores the point, and I think Richard followed it, and I would really urge people, so if there are 80,000 people around Chicago, people across the country living with these sorts of symptoms, I think my personal view is you want to consult with an epilepsy subspecialist in neurology and have a consultation so you understand the full range of treatment that may be right for you.

Also, if you've been on medication for a long time but there are side effects, are there newer medications? Are there other dosages that may make life better for you? Quality of life matters a lot.

Let's go to some e-mail questions, Dr. Schuele. Here's one from Linda in Chicago and she writes in, "After really busy days when I get home and settle down at night seizures begin. The problem is I don't even know I get them at all unless someone tells me. Now I live on my own and it makes things harder, and if I phone someone like a friend I don't even know I called them sometimes afterwards or even what I said. Is this common, and what can I do about it?"

Dr. Schuele:

I think that's a very good illustration of what many patients with epilepsy experience, and I have a number of patients who underestimate the risk of their seizures just because they are not aware of the time gap they have. They don't have a warning like Richard does. They don't have a post seizure phase of confusion or speech problems which tells them, well, something must have happened. Some of them might recognize that the movie they were just watching might have jumped ahead unexpectedly, but if they are not following something on TV or recognizing that they lost their train of thought, they might be unaware of their seizures. That is obviously the case in the evening but it is obviously the case at night.

If these are frequent it's another reason for us to I think admit patients to clarify how do your seizures look. Is there any way to recognize them for you? How frequent are they? If you're concern that you have frequent seizures, you know, that you have seizures at night and that's why you wake up in the morning with a headache or you have indirect signs that you have seizures by your bed being in disarray of muscle soreness or tongue bite, then I think that is another reason why we monitor and try to give the feedback patients with epilepsy sometimes need.

Andrew:

So that's where that sort of video EEG comes in, it would seem?

Dr. Schuele:

Yeah. I think so.

Menstruation and Seizures

Andrew:

Okay. He's a question we got from Mandy also in Chicago. Mandy writes in, "I notice whenever I'm menstruating I have auras and my brain feels off. I know that it's been documented that there is a connection between hormones and seizure activity. Is there anything you can take around that time that helps counteract these spells? I've been grand mal seizure-free for some time, but these spells around my cycle make it difficult to function."

Dr. Schuele:

Yeah, that's a hundred-year-old question, and I wish I had the definitive answer for it. We know already for that long length time of time that there's an association of seizures with menstruation, and we call them catamennial or perimenstrual seizures. And we know that many seizures in women cluster around the time of the period.

There have been recent trials going on to look for medications which could be taken to prevent at that clustering. Obviously if that is clearly predictable, and in some patients it is, there is a chance to take medications maybe for just a few days. But there is a certain risk of starting a medication and stopping it just by itself. So I think it's a very interesting area because I think many patients recognize that connection. It requires a relatively detailed evaluation of what are these spells, how bothersome are they, and what can we do about it.

Andrew:

Okay. But it's certainly known and she can investigate it further.

Dr. Schuele:

Yes.

Auras and Partial Seizures

Andrew:

Here's a question from Sherry in Salt Lake City. She writes, "I don't think I have epilepsy but I do have auras and/or simple partial seizures. I have not lost consciousness to my knowledge but definitely have the symptoms described as auras or simple partial seizures. Is this a mild form of epilepsy or can these occurrences be caused by something else? I'm on Wellbutrin XL for depression, and I know it can cause seizures," she says, "but I had these symptoms long before I started the drug. Any advice would be great. Also, are these in fact seizures? Will it eventually get worse or is this all I can expect?"

So she's really asking about side effects of the medicine although she said she's had this problem before. Any guidance there, Doctor?

Dr. Schuele:

There's a couple of interesting aspects. The one is that to diagnosis auras is very difficult because auras are very subjective to something happening in us. And to make it more complicated some of the more frequent auras we call déjà vu experiences, experiences of things which happen before, actually can be normal. We all know that we've been in a situation where we think this has happened before. And it's sometimes brought on because we don't sleep and things like that. And they are not epileptic. If you would do an EEG at the time you wouldn't record abnormal brain wave activity.

So the question is are these auras associated with an electrical discharge of the brain like we found in Richard. And if that is the case then obviously the next question is how high is the risk that that discharge spreads to the rest of the brain and causes some temporary dysfunction of the activity of consciousness and can that endanger the patient. You know, if it's just an aura you could say, well, most patients say, I can function through the aura. But as the patient pointed out, "as far as I am aware of" I don't think I have big seizures afterwards. But she's not a hundred percent sure.

And often what I see is that patients with auras if you monitor them that is--the way we diagnose epilepsy is that many of them have an aura but some of them are actually followed by brief periods of nonresponsiveness. And if you do an EEG you actually pick up some abnormal brain waves. So that brings it a little bit along why is it important to make a clear diagnosis is it epileptic or nonepileptic.

And the other point, Wellbutrin is a very, very good psychiatric drug. Many patients I know with a psychiatric condition have been very happy of being on it. But I have to say as an epileptologist it's probably one of the worst drugs in provoking seizure, epileptic seizures. So I think unfortunately it's one of the situations where a maybe/maybe not answer is not good enough, because I think that if she does have epileptic auras then she shouldn't be on Wellbutrin. That is setting yourself up for disaster.

But on the other hand there is a certain chance that the auras are not epileptic, that they are a normal phenomenon. And in that case it would be a pity to leave the Wellbutrin out. So I think that's another reason to really see a specialist and really get a black and white answer for that, a straight answer.

Andrew:

Okay. Good advice to Sherry. So Sherry, there you go. You want to investigate it further.

We're going to take another brief break, and when we come back we've got some more e-mail questions for Dr. Schuele. We're also going to get some advice from

Richard Newman. So, imagine, he had been living with epilepsy for 43 years. Now he's getting some relief, and he's in that percentage people who didn't really respond to medicines and where surgery was indicated, but most importantly he connected with specialists who could help.

We'll be back with more Patient Power right after this sponsored by Northwestern Memorial Hospital.

Andrew:

We do this every two weeks with Northwestern Memorial Hospital, Patient Power webcasts with a specialist. On November 27th we're going to be back with I guess another neurologist, Dr. Cindy Zadikoff, and we're going to discuss Parkinson's disease and get an update on that. So that's Tuesday, November 27th at 7:00 p.m. Central.

Let's go back to our discussion of seizures, both epileptic and non, with Dr. Stephen Schuele who is the director of the Northwestern University Comprehensive Epilepsy Center at Northwestern Memorial Hospital. And we have with us also Richard Newman from Skokie, who is doing quite well now.

And you're like a computer systems engineer, is that what you'd call yourself, Richard?

Richard:

I'm an applications designer. I mean, computers is such a wide industry there's all sorts of specializations.

Andrew:

Right. Well, you've got to be sharp. And I think it's great that first of all with the control of your epilepsy with both the medications you had and now with the surgery, you have a pretty demanding job, I would think. So we have to make it clear to people that although the diagnosis of epilepsy can be scary people can live full lives, and you certainly have, right?

Richard:

Yes.

Side Effects of Medication

Andrew:

There you go. Well, that's reassuring.

Dr. Schuele, here's some other questions. You're going to have to help me with this one. This is sort of a medication side effects question. I know it came up as we were talking about Wellbutrin. But Gary from Milwaukee writes in, "Due to the side effects of"--I can't even say it. You'll have to pronounce this one for me. Carbamazepine?

Dr. Schuele:
Carbamazepine.

Andrew:
There you go. "my neurologist wants start me on another drug, Keppra. I read about Keppra, and I must say that the behavioral side effects sound terrible. My question is Do they subside over time? Are they dose-related? Does titrating the dose up, does that prevent side effects" that he's worried about, "rage or emotional outbursts?"

So I guess the question, the deeper question is, whether it's Keppra or not, how do you get the dose right for someone?

Dr. Schuele:
Yes. The good thing nowadays with over ten antiepileptic medications on the market is that you usually are able to find the right medication for the right patient. Meaning, luckily patients don't have side effects to all medications. They tend to have an intolerable side effect to carbamazepine, which is usually a well tolerated drug, but some people have skin rash or they have low sodium or they feel too tired on the medication. So probably, I would say, about 80 percent of patients tolerate it quite well, but there are 20 percent who have to choose or choose to try something different.

And similarly Keppra is a medication where I would say two-thirds of patients don't have any behavioral side effects, not at a lower dose and also not at a higher dose. But there is probably about a third of patients who have behavioral side effects. And that is something if that happens I don't think there is much you can do about it. It might be in part dose-related, but I think with the options we have right now I usually recommend to patients who feel that he--if he doesn't like what the medication makes of him or that his wife doesn't like what happens with him, which is another good reason, then to switch to a different medication.

I think what I am trying to point out is that there is this high percentage of that it's just going to be fine. Meaning it's better to look and find out if it works, and if it doesn't work just switch to a completely different medication. Behavioral side effects, yes, they are relatively frequent. There are about a third of patients who have them.

Seeking a Specialist

Andrew:

Okay. I've seen this in so many health conditions. It's important for someone taking a daily medicine to have an active dialogue with their healthcare team. You're on the lookout for side effects, could be dose-related, could not be the right medication for you but in many cases the original prescription was right. And so there's that active dialogue.

And then, as you mentioned, Dr. Schuele, there's a percentage of people where medications won't do the job and that's where an approach like a surgical approach in the right hands as I think surgeons like to say can make a big difference.

Richard, let me ask you a question. So I keep preaching generally on Patient Power that people should really seek out subspecialists for their condition, and you did, I know. How do you feel about how it's worked out for you, and what would you say to other people?

Richard:

I looked at specialists in this from the beginning. I worked with--I actually can't remember the physician's name who was in what was called [?] Billings at that time, University of Chicago, to look at this. The technology was not even remotely what was there today because they didn't find out much from the EEG.

I eventually went to another one who was a specialist in it, Nick Vick, who I think is in the Evanston Hospital now, but you would know that more than me, Doctor. I ended up with Dr. Kanner at Rush Presbyterian, Presbyterian St. Luke's, but my company's medical program no longer recognized them as in their program, so it was financially too serious for me to stay there. Dr. Kanner recommended Dr. Schuele, and I already knew from my own research that there are three hospitals in this area that are specialists in epilepsy which would be UC, Northwestern and St. Luke's Presbyterian.

Andrew:

Right, and you got to Northwestern. So the point though is if somebody is out there and they're not confident that they've seen someone who really I like to say eats, drinks and sleeps their condition, it sounds like to me that you got the best care because you saw a specialist like that.

Richard:

I believe so.

Andrew:

I think so, too.

Richard:

As the doctor said, though, when I got it 40 years ago or more, they only had drugs like Dilantin or phenobarbital and Mysoline and a couple others, where they would give you stuff but their side effects could be problematic, I'll put it that way.

Andrew:

Right. Come a long, long way. So that's my final question, actually, for you, Dr. Schuele, and that is you've been at this quite a while too, I take it. How do you feel about the quality of care and the diagnostic and the personalized care you can give now for people with these recurrent seizures and where we're headed so that people can live a full life?

Dr. Schuele:

I think we're just about to take off. I think Richard's experience in Chicago is that we're very collegial and cooperative. There are three major centers for epilepsy. But at the end there are probably only about ten real specialists for epilepsy in the city, maybe 15. And it's important I think, the epilepsy care has so evolved that many of the primary care physicians and general neurologists who also take care of epilepsy patients in the local communities start to refer patients to these big centers for a second opinion, for an evaluation of seizures, if they are not clear if they're epileptic or not. They want to find out if a patient is a surgical candidate. They've tried several medications and they want some feedback if there's something better they can do.

Andrew:

Right. We've got to go, Dr. Schuele in our 60-minute time frame here. But that was Dr. Stephen Schuele at Northwestern. He's the director of the epilepsy center there. I think the point is connect with quality care. I'm really proud that Northwestern Memorial has it.

All the best to you too, Richard.

This is what we do on Patient Power. So revisit our replay on healthnet.nmh.org. And join us again on the 27th if it's appropriate for you when we discuss Parkinson's. Take care. Knowledge can be the best medicine of all. I'm Andrew Schorr. Have a good night.

Please remember the opinions expressed on Patient Power are not necessarily the views of Northwestern Memorial Hospital, its medical staff or Patient Power. Our discussions are not a substitute for seeking medical advice or care from your own doctor. That's how you'll get care that's most appropriate for you.