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>> Well, welcome back to Health Link on Air brought to you each week by University Hospital, making the academic difference in healthcare in the Central New York community. And this is your host Tricia Torrey, every patient's advocate. Well you know, we've talked with guests before about brain-related conditions and diseases. But this morning we're going to talk about a disorder we have not covered before, epilepsy. In the studio with me this morning are Doctor Helen Barkan, Assistant Professor of Neurology at SUNY Upstate. Good morning, Doctor Barkan.

>> Good morning.

>> And Doctor Robert Beach who's the director of the epilepsy program, and Associate Professor of Neurology at Upstate. Good morning, Doctor Beach.

>> Good morning.

>> Epilepsy, I think it's one of those conditions we think we know something about, but we probably don't know too much. Doctor Beach, will you explain exactly what epilepsy is?

>> Well epilepsy is defined as a tendency to have unprovoked seizures, and that means that you can have seizures that are caused by disturbances such as severe sleep deprivation or metabolic disturbances like changes in your diabetic control. But if you have them recurrently and unprovoked, then you have epilepsy.

>> I see. Are there a lot of people with epilepsy in Central New York?

>> The incidence nationwide and in central New York is approximately point five percent. It's a little more common in the very young and the very old. But there are not major geographic differences within this country.

>> There aren't. How many Americans have epilepsy?

>> Estimate would be in the neighborhood of three percent.

>> Three percent?

>> I'm sorry, three million.

>> Ah, three million. Okay. Three million people, that's still, that's quite a large number, isn't it?

>> Yes, that's quite a large number. It's one of the more common, and it's a fairly easily defined disease because you have fairly rigorous criteria for what makes it.

>> If someone's having a seizure and I'm in the same room, what do I observe, what do I see happening?

>> Well it does depend upon what kind of seizure they have. There are seizures that are very subtle that people often do not notice. Childhood absence [assumed spelling] epilepsy is a brief interruption of the patient's activity which can go unnoticed, but if the patient is speaking or doing something active, is likely to be noticed. In adults or older people, complex partial seizures are more important, and these often are unnoticed if the person is not being interacted with. More severe seizures like motor seizures and convulsions are generalized tonic clonic seizures are very violent activity that are seldom unnoticed, and they can involve a patient dropping to the ground, stiffening and jerking, and perhaps having some respiratory difficulty afterwards, and being quite somnolent or tired afterwards.

>> Doctor Barkan, I've heard terms, and I remember hearing them many years ago, grand mal, petit mal describing these seizures, and I think that was supposed to be the category of the seizure. Do we still use that kind of terminology?

>> We try not to. These are outdated and largely misused terms. However, if a patient chooses to describe his or her seizures by those terms, we respect that and we work with them and we call them that, understanding that these are no longer accepted terms.

>> Mm-hmm.

>> When patients say grand mal, they usually mean that they're having a convulsive episode or something involving motor activity, thrashing and falling to the ground. And they usually lump everything else with petit mal.

>> They do? I see. If I observe somebody having a seizure, should I be helping that person?

>> Yes.

>> Okay.

>> But not, in the old times they used to say that you should put a spoon or something in their mouth, but that is no longer true.

>> So they wouldn't swallow their tongue, that's what I remember hearing, yes.

>> Right. They usually don't. The only thing that you have to make sure is that they're in a safe situation where they are on their side, preferably, and no loose clothing or loose bedding is around their face, that you can see them breathing. And they're not somewhere where they can fall.

>> Okay.

>> And harm themselves. But that's basically all you can do is observe and make sure that they're safe. Holding them down is not a good idea.

>> Just kind of leave them alone and make sure they're safe. Once the seizure is over with, do they just get up and go on as normal?

>> Rarely. If it's a truly convulsive seizure, people are likely to have a confusional state after it, which may last up to a day or even more. But usually lasts about an hour or so. They may sleep, or they may be very confused. Certain types of seizures that are non-convulsive, the people indeed jump right out of them and right back into their backgrounds.

>> They do, they do. Doctor Beach, what causes seizures? Are there specific triggers that you know of?

>> Because you asked triggers, I'm assuming you're asking about causes in the sense of an acute event, because there are causes of epilepsy that are multiple and involve a lot of different things such as malformations of the brain, injuries or infections of the brain, or genetic causes. But in terms of provoking a seizure in a person who has epilepsy, or causing a seizure in that sense, the most common cause of somebody who's actually treated for epilepsy is missed medications. Many people cannot be completely controlled, and there are factors within life that trigger seizures in susceptible people, and probably one of the three of us at the table here, if adequately provoked, could have a seizure.

>> Really?

>> If we're kept up for like seven days, or for a seizure patient much less, sleep deprivation is an important trigger. Stress is an important trigger and any kind of metabolic problems such as an illness and some drugs can precipitate seizures.

>> Seizures, but are they all epilepsy?

>> Well, if they're in an epileptic, they're epilepsy, but many unprovoked seizures occur in the population. The overall incidence of a seizure in the life of a person in the United States is approximately ten percent.

>> Ah-hah.

>> And as you heard before, most of those people do not have epilepsy, and most of those are provoked by some sort of transient, sometimes repeated, but transient occurrence.

>> All right. Well if we stick with the topic of epilepsy, tell me what causes epilepsy. Is it genetic?

>> There is a significant number of cases of epilepsy that are genetic. And these are often grouped into syndromes that have either an identified gene or a set of areas on a chromosome that are associated with them, or just simply show a strong familial tendency without a identified gene. And these are rather small groups, but there are a couple of genetic ones that are large like childhood absence epilepsy where the genes haven't been identified. But many of the epilepsies, and I'm not sure the fraction, but probably a greater fraction in adults certainly, and beyond the twenties are caused by things other than genetics. They may be caused by things that occurred during development, like a slight abnormality in the way the brain was formed.

>> Mm-hmm.

>> Or they may be caused by an injury or infection that occurred to the brain earlier. Or a stroke in the older population becomes the most significant cause of new onset, and of course brain tumors.

>> How do you diagnose epilepsy then to tell that there's a difference between someone who's just had a seizure that would be rare, as opposed to someone who's developed epilepsy?

>> Well usually history is the most important thing, because many times people present with a single obvious witness seizure, and yet historically you can identify events that probably were seizure in the past.

>> They just didn't know it.

>> They weren't seen, they weren't identified, or they were more subtle than the ones that may have gone on to more severe seizures. We also use tests. The most common one is the EEG and MRI looking at the structure of the brain is also a very important test.

>> And you can observe it in the brain?

>> Frequently you can see an abnormality on the EEG and the MRI, but not always.

>> Now you have an epilepsy program at University Hospital. Can you tell me more about the epilepsy program, Doctor Barkan?

>> Well in a way I'm new here, so I think I'll defer this question to Doctor Beach.

>> Okay.

>> I can only tell you that from my three, almost three months here, I can say that this is a state of the art program, and I came from the Mayo Clinic prior to that and trained there and trained at Dartmouth Hitchcock Medical Center, and saw some other major centers, so I think we do have here a very state of the art thing going.

>> There you go. It's kind of an outsider's point of view. That's excellent. Well Doctor Beach, tell me about your program, cause I think this sounds like a wonderful resource for people who are worried that epilepsy is getting in the way of their lives.

>> Yes, we try to offer all varieties of treatment, and I'm really glad that Doctor Barkan got a chance to introduce her background because she's a wonderful addition to our program here, and really enables us to see patients much more quickly than we have in the past. We offer a variety of treatment options and diagnostic options. Diagnostically, probably the most significant option is getting a good quality EEG, or an extended EEG when a normal EEG may not show up something. We also offer a number of treatment options from medications that are in use, being used under the most sophisticated means. We also have experimental drug trials and experimental trials of things like the gamma knife for treatment of focal, intractable epilepsy.

>> So there are surgical options as well as pharmaceutical drugs that you give to patients. And I have to think that somebody with epilepsy, this has to get in the way of their lives. And I have to think that would be your goal then, to make sure that it doesn't affect their lives any more negatively than it has to?

>> Yes. Epilepsy, the burden of epilepsy has been estimated in millions and millions of dollars of both medical and other issues. The person with epilepsy is frequently discriminated against. Whether it's in school or in the workplace, people have an almost mysterious fear of this disease.

>> Because they don't understand it.

>> We have gone to court to try to protect patients from discrimination at the workplace.

>> Really.

>> There is, those people cannot drive in most states, well, all states have rules that limit people with none epilepsy, take their drivers license away, and periods are usually six months to a year that they have to be seizure free. And of course, for women there's always a big question of, can I have children.

>> And can they?

>> Yes, the answer is yes you can, but you have to be followed very closely. Your medications may need to be changed or adjusted to optimize treatment, and to minimize risk to the baby. But yes, they can. But to summarize, the burden of epilepsy's enormous, and the joy of this profession is being able to sometimes bring the person back to the workplace, back to their families, and back to their life which they basically have lost to seizures.

>> Excellent. Well I think that a lot of understanding is what helps these kinds of things out there in the world for patients with epilepsy. We'll make sure that patients or their families can contact you. We'll put information on our Healthlink on air website so they can find you. Doctor Helen Barkan and Doctor Robert Beach, thank you so much for coming by this morning.

>> My pleasure.

>> Thank you. It's been an honor.

[background music]

>> Listeners, we need to take a break now, but it won't be long before we return. Please stay with us. This is University Hospital's Health Link on Air on five seventy, WSYR.

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>> Well, welcome back to Health Link on Air brought to you each week by University Hospital, making the academic difference in healthcare in the Central New York community. This is your host, Tricia Torrey, every patient's advocate. Fast becoming one of our regular guests, we have Doctor Donna Bacci [assumed spelling] in the studio with us this morning. Good morning, Doctor Bacci.

>> Good morning.

>> And listeners, you may remember that Doctor Bacci is an Associate Professor of Pediatrics at SUNY Upstate and works with the Onondaga County's Public Health Department. We're also joined by Cathleen Cofflin. Good morning, Cathleen.

>> Good morning.

>> Cathleen's the Project Director at the Syracuse Healthy Start Program which works to decrease infant mortality in the city of Syracuse. This morning, we're going to discuss something that I've learned is a large problem in Onondaga County. Listeners, when I tell you about this, you're going to be surprised and appalled as I was. This is infant safe sleep month, and Doctor Bacci, tell us why a month has been set aside for safe sleeping for infants.

>> Well, we used to think this broad category of SIDS was just unexplained deaths that we didn't know we could do anything about that weren't preventable. But we now know that there's a significant number of those deaths that are preventable. In fact, in the last five years in Onondaga County, there've been about twenty unexpected deaths and about seventy-five percent of them can be attributed to unsafe sleeping situations of infants.

>> Wow, seventy-five percent of them, that's fifteen of the children.

>> Yes.

>> All right, now SIDS, let's make sure we explain stands for -

>> Sudden Infant Death Syndrome.

>> Right.

>> It's a death of an infant under the age of one that you don't have a diagnosis for. The baby's not premature, didn't have some kind of a malformation or some kind of other problem.

>> So therefore, it was un-attributable.

>> Yes.

>> These babies, you kind of get up in the morning and go and find that you baby had died in the night.

>> Or at some point during the day.

>> I just cannot imagine how a parent would feel when something like that would happen. Now you've found that seventy-five percent of them can be, perhaps, prevented?

>> Yes. There are things called, well, what we're finding is that some of those children have been sleeping in a regular bed with parents or siblings on a soft mattress. Some of them are being put on a couch or, you know, sleeping with their parents or put on a couch to sleep. And what happens is an infant, particularly an infant under six months of age, doesn't have the muscle strength that if they're starting to get suffocated where they can't breath to really move their head and move themselves out of the way like a lot of us would.

>> I see.

>> And so, we're finding that those deaths really are preventable if parents, there are a couple of things that parents can do. One is to put children on their back to sleep because we know that we used to put them on the prone position. We know that there's an increased risk of SIDS if they are so put them on their back.

>> Prone position means -

>> Means on their stomachs.

>> On their stomachs.

>> So put them on their back to sleep.

>> Okay.

>> Not to, put them on a firm surface, so not on a waterbed, not a regular sofa, not on a regular bed. That [inaudible] being is a risk factor so have the child sleep in their own crib, not in the bed with the parents or with other children, not on a couch. And also, smoking increases the risk of SIDS.

>> It does.

>> Yes.

>> Wow, okay, we're going to dissect all of this and break it down and make sure that parents are very clear on how they wanna make sure their infants are going to sleep. And before we actually get into those details, I wanna ask you, Cathleen, you work with the city of Syracuse, right?

>> Yes.

>> Are the statistics similar to Onondaga County?

>> Yes. We're not seeing any difference between city and county, between level of education, class, race, any of those types of things. This is a problem that's really affecting every parent in Onondaga County and in Central New York.

>> And then, if seventy-five percent of them can be fixed, then that's what parents need to pay attention to is that seventy-five percent of the things that they can control. All right. So let's go back. The first thing you were saying is about environmental kinds of things. Make sure they're on a firm surface, is that right? Is that what you were saying?

>> Make sure they're in their own crib.

>> Okay.

>> On a firm mattress.

>> On a firm mattress.

>> With nothing around them so no bumpers on the bed, no blankets, no toys, no other things that the child could accidentally roll into and be in a situation where they couldn't get out.

>> Okay. Now, I know recently in the headlines, there's been something about cribs that were defective. Do you want to address that, too?

>> Well, certainly, we need to make sure, and I know those were modern cribs but a lot of the older cribs, the slats or the space between the bars on the cribs was wide enough so that an infant could get their head through. So they have now closed that so most modern cribs should have

slats or the width of those slats small enough so an infant couldn't accidentally put their head through it. But the other thing is you have to make sure that you're putting the crib together appropriately and that the crib is made appropriately. Certainly, people need to look on the consumer product website to make sure that their particular crib is not one that's been recalled.

>> All right. And you know, we'll put a link to that website from our Health Link on Air website. And also, isn't there a question about the size of the mattress in relation to the size of the crib?

>> You want a tight, snug fitting mattress in the crib. I always tell people, if you're having a hard time changing the sheet on your baby's crib, that means that the mattress is probably just right. You want to make sure that there's no space in between the mattress and the edge of the crib itself where the baby can get stuck.

>> Right. Because their little heads can get stuck in there, can't they?

>> Absolutely.

>> Oh, my gosh. That would be horrible. Now, what about, you know, there are a lot of parents and you hear this debate, they like the idea of the baby sleeping in the bed with them. And it seems like what you're saying here, that just doesn't work, does it?

>> No. We're trying to push the idea of room sharing is safer than bed sharing. So especially, even if the mom is breast feeding, get a small bassinet, put it next to your bed so that the baby's within an arms reach. You can pick her up, you can nurse her and put her straight back. We're trying to teach parents that whether breast fed or bottle fed, you just want to make sure that the baby is not in the bed with you and just right next to you instead.

>> I see. So, in this case, what you're talking about is a bassinet that is like we talked about the crib, the mattress fits well. There aren't extra blankets. Would that be right, Doctor Bacci?

>> Correct.

>> You don't have other things in there as well. Okay. Let's talk for a minute about how the baby sleeps. Now, you mentioned earlier that the baby needs to sleep on his back.

>> On their back, yes.

>> And you know, when my kids were little, we were told to put them on their tummies. Why are we saying put them on their back now?

>> Well, we found that a lot of research has shown that Sudden Infant Death Syndrome has increased in babies who sleep on their tummy. And even on their sides. So we're really recommending that parents put their children on their back to sleep.

>> All right. So what I remember is, my kids had those little mobiles but because I was supposed to put them on their tummy, they couldn't see them anyway. Is it okay to have one of those mobiles hanging over the bed?

>> As long as it's high enough that the child can't grab and remove something, yes, it's fine.

>> That's okay. And you know, they also get to a point where they're old enough that they begin to roll over. So tell me about that. What happens when they roll over? Am I supposed to put the baby back on his back?

>> Well, you continue to put the baby on the back when you put them to sleep. Just make sure the crib is tight-fitting, that there's no other things in the bed where the baby can potentially scoot and not be able to get away.

>> Okay. At the point, too, a lot of this has to do with the fact that the baby doesn't have the muscle tone, I guess, to be able to get himself out of a suffocating position. If they get to the point where they're turning over, does that mean they kind of have that muscle tone built in then?

>> They're starting to and that's, you know, one of the things we also encourage is because we put babies on their back now is to have parents give babies tummy time. So they get the opportunity to kind of use their arms and start lifting their head up, otherwise, they may have problems and not develop that as early as possible.

>> Yeah, and tummy time, I love that name for it. But you can also, I mean, you put the baby down on a blanket on the floor. There are other times they can be working on doing their little pushups, right?

>> Correct.

>> And learning how to crawl even, eventually, from there, too, isn't it? Well, is there anything else we need to know about safe sleep month? Anything else parents need to be aware of to keep their babies safe?

>> Well, there's a lot going on in the community this month. There's actually an organization, it's a group of community organizations that have come together for the Partners in Education and Prevention of Unexpected Infant Death. And that's the health department from both Onondaga and Madison. It's the New York State Center for Sudden Infant Death, (inaudible) and a couple of other community organizations. What they will be doing is they, our group is going to be giving presentations to all the area birthing hospitals for staff about the importance of safe sleep. There'll also be onesies distributed at all the birthing hospitals during the month of October. So every mom out there who's gonna be delivering at Kraus Community or Saint Joe's will be receiving a onesie that has the ABCs of safe sleep which stands for Alone By himself in a Crib. So we just really want to make sure that all those new parents go home with the idea that their baby should sleep by themselves. We're also gonna be running commercials and distributing information in all the obstetricians in the city of Syracuse.

>> Excellent.

>> And also in Madison County because we just want to make sure that it gets out and that the medical community knows as well as the moms and dads in our area.

>> It really is a question of awareness then, isn't it? Well, Doctor Donna Bacci and Cathleen Cofflin, thank you so much for coming by this morning. This is a topic that, you know, if you don't have babies in the house, you might not think about. But I know I'll be talking to my friends about it. They have grandchildren and they'll want to hear this. Thanks so much for coming by this morning.

[background music]

>> Thank you.

>> Thank you.

>> And listeners, we do need to take a break now but we'll be back soon. This is University Hospitals' Health Link on Air on five seventy, WXYR.

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