



All About Epilepsy

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Why learn about epilepsy?

Epilepsy is a word that means seizures. Sometimes epilepsy is called a seizure disorder.

Lots of people in the world have seizures, and lots of children do, too. Most of them do just the same kinds of things that other children do.

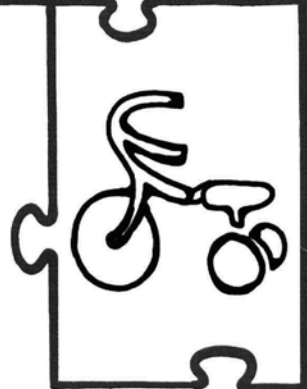
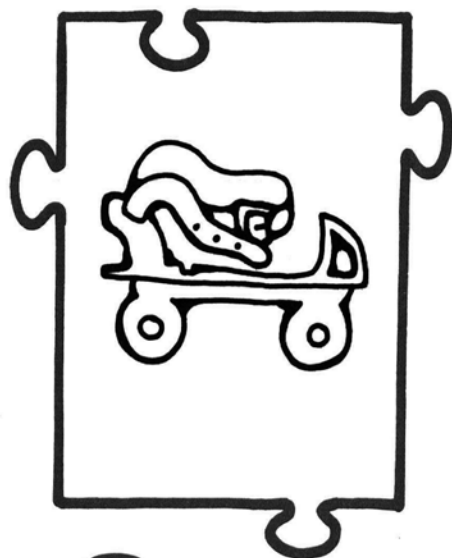
They run and play.
They go to school.
They have friends.
They have fun.

Seizures only last a few minutes.
Some only last a few seconds.
So seizures are only a part of a person's life.

But if you have epilepsy, or if someone in your family has epilepsy, it is good to know as much about it as you can.

Because if **you** know about epilepsy, you can explain it to other people so they will understand.

That's what this booklet is all about.



Why seizures happen

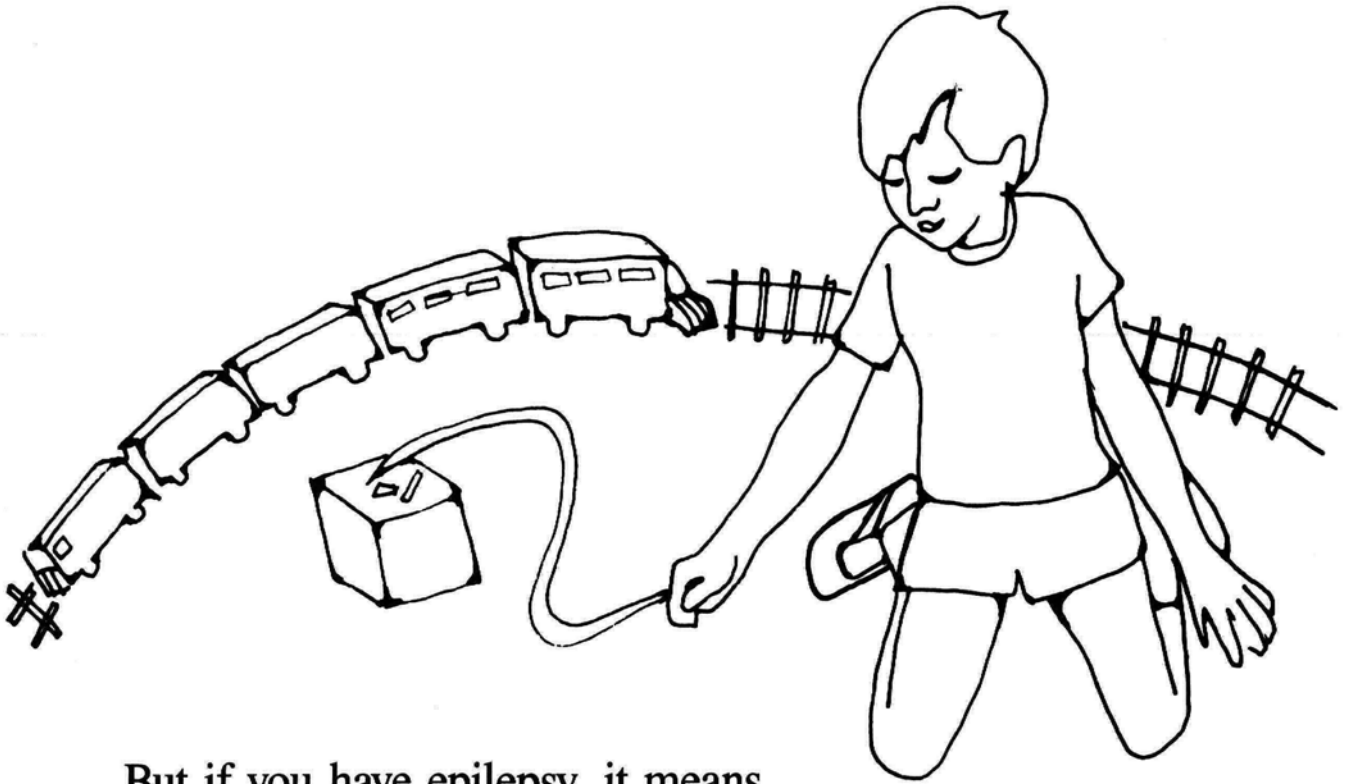
Seizures begin in the wonderful network of cells in your brain, cells that make your brain and your body work.

These brain cells are a bit like the batteries that you put in a toy. When you turn the switch on the toy the electricity stored in the batteries makes the toy work.

Your brain cells store electricity, too. When you want to do something, special cells in your brain send electrical messages to different parts of your body to make them work.

Cells in different parts of your brain make different parts of your body work. Some parts make your arms or legs move. Some parts make you see. Some parts make you hear or speak.

And most of the time all those millions of cells work just fine. They send millions of tiny messages every day. And it all happens without your even having to think about it.



But if you have epilepsy, it means that you have some brain cells that sometimes do not work in the right way. For a short time—maybe just a few moments, or a few minutes—these cells send out **more** electricity than they should. They stop the other cells from doing their work properly, and your body gets mixed up messages.

These mixed up messages change the way your body works for a short time. These changes are what we call seizures.

There are different kinds of seizures.

- One kind makes you stop and stare for a few minutes.
- Another kind makes you fall down and shake all over.
- Another kind makes you do things as if you were doing them in your sleep.

There are other kinds of seizures, too, but these are the kinds that most people with epilepsy have. You may have just one kind of seizure, or you may be one of those people who have more than one kind.

But whichever kind of seizure you have (or someone you know has), they are all caused by the same thing—that extra electricity from some cells in your brain.

José has epilepsy

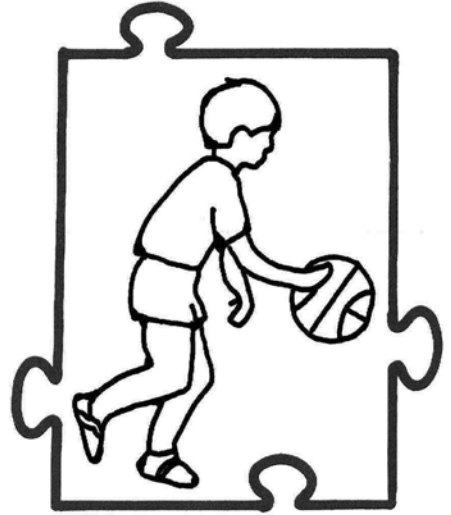
José Sanchez is ten years old. He likes sports, especially basketball. He belongs to the Cub Scouts and is good at math. He wants to be a drummer when he grows up.

José has epilepsy. When he has a seizure he falls down and his body gets very stiff. Then his muscles begin to jerk (because they're getting too many electrical messages from his brain all at once). His whole body shakes for a few minutes.

José does not know what is happening to him while the seizure is going on. To him it is like being asleep.

Sometimes he wets his pants during a seizure, which makes him feel very embarrassed afterwards. But he knows he couldn't help it. It was the seizure that made it happen.

José's seizures only last a few minutes. Then they stop by themselves,



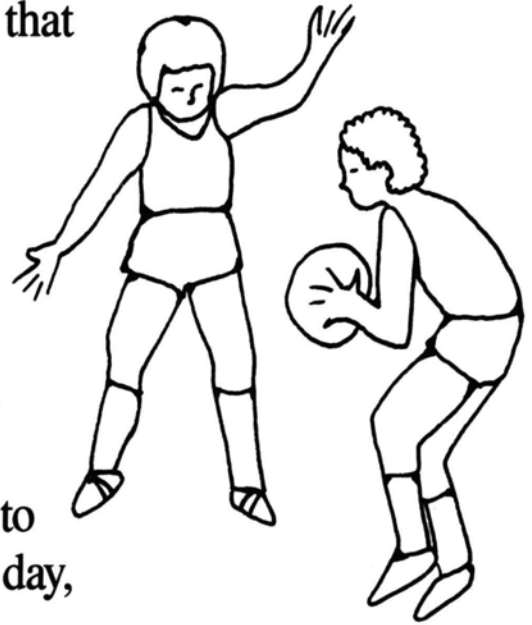
and everything starts working properly again. He usually feels sleepy and a bit confused after a seizure, but after a short rest he likes to go back to what he was doing before the seizure started.

Another name for José's kind of seizure is a **convulsion**. The doctor may call it a **generalized tonic clonic** seizure or a **grand mal** seizure. Some people may call what happened to José a **fit** because they don't know that the correct word is a seizure. In some parts of the country people call José's kind of seizure **falling out** or a **falling out spell**.



José likes sports, so his mother asked the doctor if it would be all right for him to play basketball. She thought a lot of exercise and playing hard might make José have more seizures. But the doctor said it was good for José to get out and play with his friends and it would not make him have more seizures.

José was glad to hear the doctor say that because he likes basketball very much. He was pleased when the doctor said he could go to camp, too. His best friends were going.

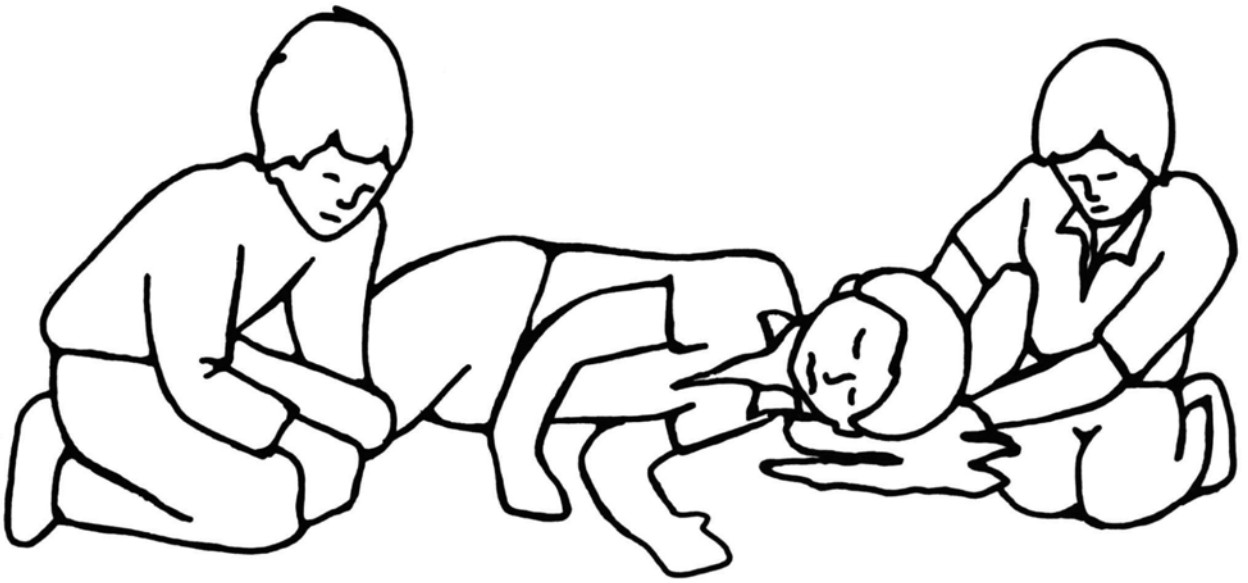


When José went to camp his mother gave the camp director his medicine, the pills that he takes to stop seizures from happening. She asked the camp director to make sure that José got his pills twice a day, as the doctor had said.

“What will you do if you have a seizure at camp?” said José’s mother when they were packing his things.

“I thought about that,” said José. “I told my friends what to do. I told them what Dr. Clark told you to do. And they practiced doing it.

“Bill and Matt and Jason took turns pretending to have a seizure and I showed them what to do. Jason was the



best at pretending to have a seizure. Matt couldn't do it at all. He looked real funny."

José's mother was surprised. "But how do you know what your seizures look like, José?" she asked.

"From the nurse at the hospital when I went for tests," José said. "I asked her what a seizure looked like and she told me."

Then José's mother wanted him to tell her what he'd told his friends to do if he had a seizure. So he did.

"I told them to clear things out of my way and put a folded jacket under my head," he began. "Matt is going to do that. Jason will make sure I'm turned on my side, and Bill will go tell one of the counselors. Matt and Jason will stay with me till I wake up."

José's mother was surprised he had remembered so well what his doctor had said to do when someone has a seizure. She felt very proud of José.

"That was a good idea you had, José," she said. "It's good that your friends know what to do."

José had a great time at camp. He liked going in the canoe best of all. Everyone wore life vests and everyone learned how to use the canoe paddles to move through the water. It was fun.

“The campfire was fun, too,” he told his mother when he got home. “But Bill ate so many marshmallows you wouldn’t believe it. He was sneaking everybody else’s marshmallows. He ate so many he got sick. We all laughed.”

“Did the counselor give you your medicine every day?” asked his mother.

“Yes, except he forgot one morning and then I told him. Jason was sort of sorry that I didn’t have a seizure. He wanted to practice doing what I had shown him. I’m glad I didn’t have one, though.”

“So am I,” said Jose’s mother.



Ray's brother has epilepsy

José's mother is glad that José has good friends who understand about epilepsy and what to do if someone has a seizure.

Sometimes children who don't understand epilepsy may tease a child who has a seizure. Sometimes it's a brother or sister who gets teased.

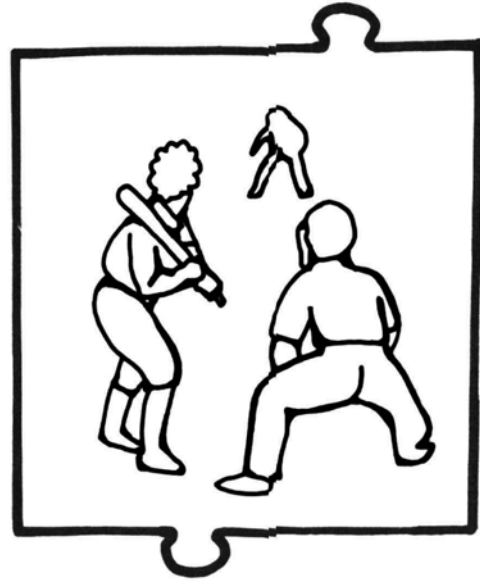
José's brother Ray found that out one day after José had a seizure on the school playground.

The next day Ray noticed that some of the kids in his class were whispering and laughing behind their hands and pointing at him.

"What's so funny?" said Ray.

"Hey, you've got a weird brother, so you must be weird, too," said one of the kids. His name was Carl.

"My brother is not weird," said Ray.



“He sure looked weird yesterday,” said Carl. “He looked crazy. He was jerking all over. That’s pretty weird.”

“Weirdo! Weirdo!” said Carl’s friends.

Ray was mad. He wanted to punch Carl.

“Yeah, well, the jerking is part of a seizure,” he said. “My brother had a seizure, that’s all. He has epilepsy and that has nothing to do with being crazy. You’re crazy to think that.”

“Epilepsy—that means you’re not very smart,” said another kid.

“Yeah, your brother’s a dummy,” said Carl.

Ray felt angrier and angrier.

“That just shows how stupid **you** are,” he said. “José’s getting an A in math from Miss Presley. I bet you didn’t get an A from Miss Presley.”

Nobody said anything for a minute.



Everyone knew about Miss Presley's math class. It was tough.

"Well, my brother's in high school and he says epilepsy runs in families, so maybe you'll get it, too—weirdo!" said Carl.

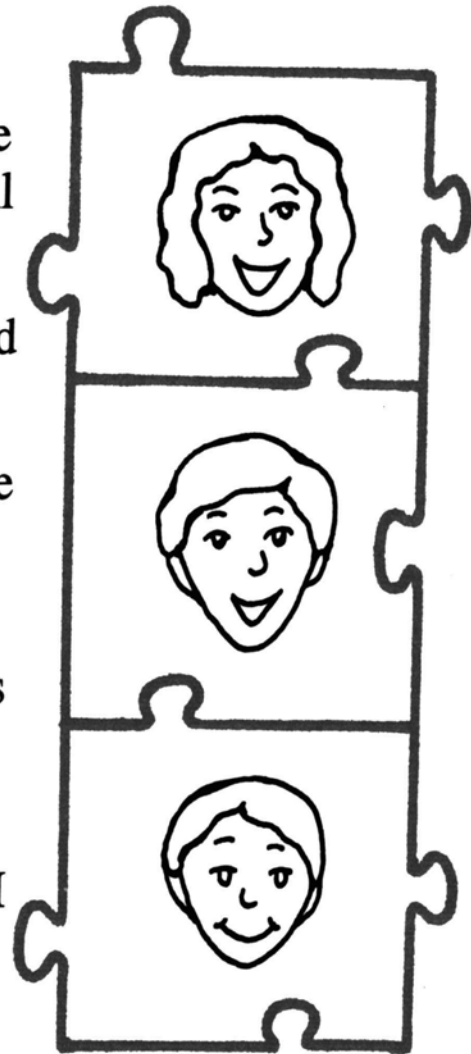
Ray went to hit him. But Carl laughed and jumped out of the way.

"Don't get mad—you'll have a seizure," he said, and ran away. Some of the others went with him. But some of the kids stayed.

"Don't pay any attention to him, Ray. He's mean," said Jenny. "He's mean to everyone."

"Hey, Ray, we don't think José's weird," said Fred. "He's real good at basketball, and I didn't think anyone could get an A from Miss Presley."

When Ray walked home that afternoon he still felt mad. He still wanted to punch Carl. He felt a bit mad at José, too.



talking about,” said his father. “Even if someone else in our family did have epilepsy, that wouldn’t mean that **you** would. As a matter of fact, **anyone** can have epilepsy.”

“Even Carl’s brother?” said Ray.

“Even Carl,” said his dad.

“Good,” said Ray. “I hope he does.”

“You’re pretty worked up about this, aren’t you?” said Ray’s father.

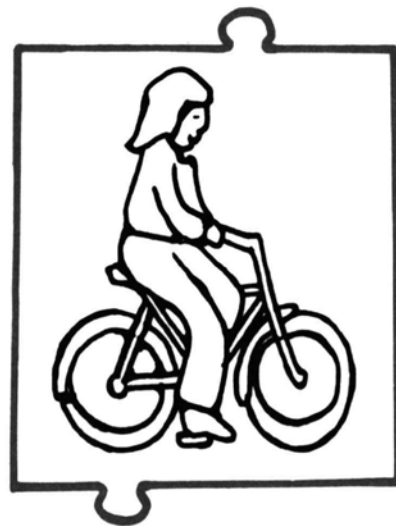
“Well, they were being so mean,” said Ray. “I’d still like to punch Carl.”

“What about the others?” said his dad. “What did they do?”

“Well, I tried to tell them that what Carl was saying was wrong. And some of them were okay then.”

“Was Carl one of your friends before this happened?” Ray’s father asked.

“No way! He’s always kind of mean,” said Ray.



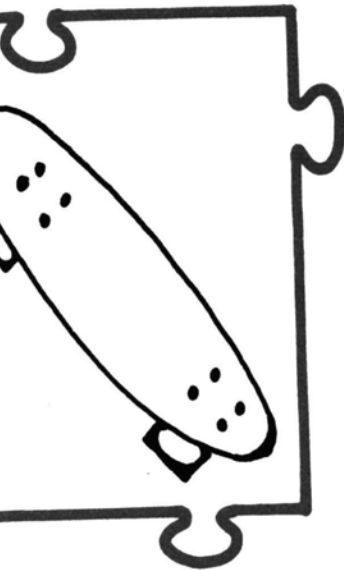
“Seems to me Carl’s the one with the problem. I wouldn’t want to go around being mean all day,” said his father.

“But some of the others were mean, too. At least, they were at first,” said Ray.

“Maybe they were scared,” his dad said. “You know, the kind of seizure José has happens so suddenly that it startles people. Almost like someone jumping out at you when you don’t expect it. But if kids know that a seizure only lasts a little while and you can’t catch it from someone else, then that scared feeling goes away.”

He thought for a minute.

“You know, I think I’ll talk with Mrs. Martin about doing a special lesson on epilepsy in her science class. I think that will help all the kids understand it better.”



“How come José had to go and get epilepsy, anyway?” said Ray. “It’s a real pain. It always seems like it’s messing things up. Like that trip we couldn’t go on last year because he had to have tests. And when he had that seizure in the movies. Dad, that was so embarrassing.”

“I guess José would agree with you about that, Ray,” his dad said. “We really don’t know why José has epilepsy. He just does. But we’re lucky that there are medicines to prevent seizures from happening, and we’re lucky that when he does have a seizure it only lasts for a short time.

“By the way,” he added, “it sort of sounds to me as if you’re mad at José a little bit, too.”

“Dad, I know it’s not José’s fault he has epilepsy,” said Ray. “And it makes me feel mean to be mad at him about it. But . . .well, I guess I am sometimes.”

“Well, we all get angry at things sometimes,” said his father. “I get angry when you kids don’t behave. I get angry with people at my shop. I get angry when my car won’t start.”

“But I’ve learned something about dealing with angry feelings, and this is what I do. When I get mad I say to myself: Can I do anything to change the things I’m mad about? If the answer is yes, I go change it. If the answer is no, you can’t do anything about it, then I do something to get rid of the angry feeling.”

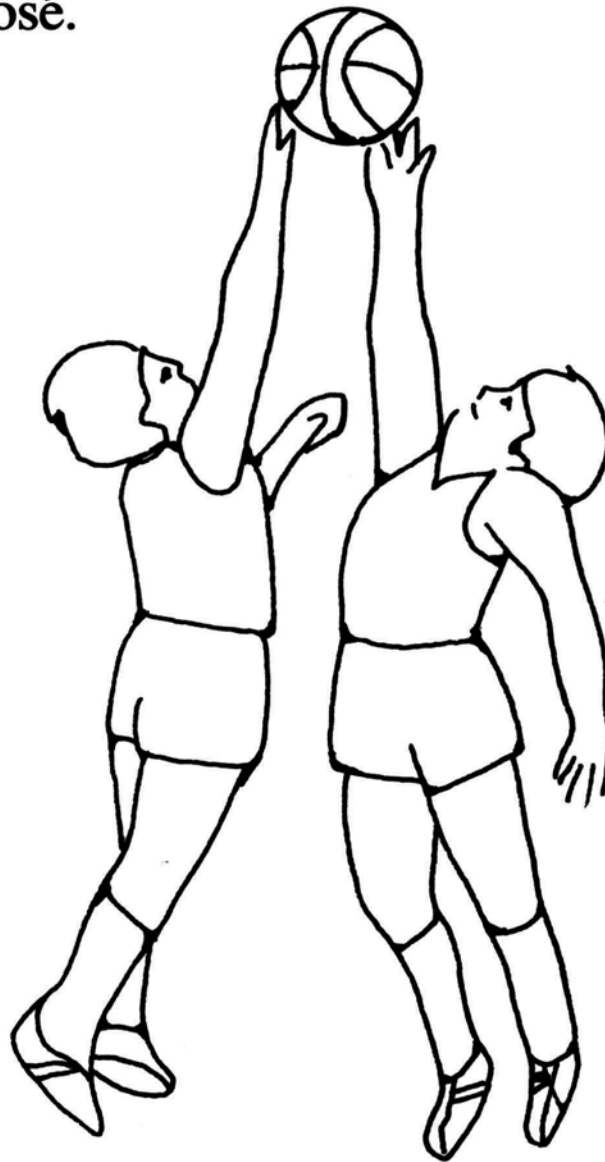
“How do you do that?” asked Ray.

“Oh, I run for a while,” said his dad. “Or I chop some wood for the fire. Or I hit a tennis ball around as hard as I can. And you know what? After I do something really energetic like that I find I don’t have those angry feelings any more.”

“Maybe I’ll try that,” said Ray.

“Hey, José,” he called up the stairs.
“Want to go play basketball? I’ll play you
one on one.”

“Sure,” said José.



Jim has epilepsy

Jim Brown is seven years old. He likes to go fishing with his dad and he collects football cards. He likes to build models, too. He tells people that when he grows up he wants to build a big bridge.

Jim has epilepsy, too. But he doesn't have the same kind of seizure that José has. Sometimes Jim's brain cells send out too much electricity, just like José's. But they only do it for a very short time—just long enough for someone to say “One thousand and one, one thousand and two, one thousand and three.”

Jim's seizures don't make him fall down, either. They make him stop what he is doing and stare for a few moments. If you say something to him when he is having one, he won't hear you. But when it is over he can go right on with what he was doing before it began.

Sometimes Jim has a small seizure like this and doesn't even know it happened. Often



his friends don't know, either, because it is over so quickly.

There are two names that people use for the kind of seizures that Jim has. They are called **absence** seizures or **petit mal** seizures.

It was Jim's second grade teacher who first noticed that Jim was having little seizures. They happened so quickly and were over so fast that not even Jim's mother had seen them.

But the teacher had had little seizures like Jim's when she was a little girl, so she called Jim's mother and told her what she had seen.

"I think I know why Jim has been having trouble with his school work," she said. "I think he has been having little seizures which have made him miss parts of the lessons."

Jim's mother took Jim to the doctor and told her what his teacher had said.

The doctor examined Jim and asked a lot of questions, writing down the answers on a big piece of paper.

When she finished writing, and after she had examined him, the doctor turned to Jim and said: “Well, Jim, you look like a pretty healthy young man to me, but I think we’ll do some special tests to see if we can find out some more about these little staring spells you’ve been having.”

The next week Jim and his father went to the hospital for the test.

“You’re going to have an EEG test,” the nurse told him. “This is Mrs. Jones. She will give you the EEG test.”

“Hullo, Jim,” said Mrs. Jones. “We’re going to paste some wires on your head, like the astronauts had when they went into space.”

Jim wasn’t so sure he liked the idea of the wires, but she told him they wouldn’t hurt at all.





“What are the wires for?” asked Jim.

“They work a bit like little telephones,” Mrs. Jones said. “They listen for the electrical signals that your brain cells make. The signals will make a row of little pens on the EEG machine move up and down. Your doctor will look at the wavy lines that the pens make on the paper. The way the lines look will help her figure out what’s making you stop and stare sometimes.”

“Can that machine tell what I’m thinking?” asked Jim.

“No,” said Mrs. Jones. “It’s a smart machine, but it’s not that smart.”

She helped Jim lie down on the couch and pasted the wires on his head with sticky stuff.

“That’s yucky,” Jim said. “It’s going to make my hair sticky.”

“Yes, it will,” said Mrs. Jones. “But it will all wash out.”

When all the wires were in place, a little light was flashed in Jim's eyes. Mrs. Jones asked him to take a lot of deep breaths. Then she said it would be a good idea if he took a nap.

“How can I take a nap with these things on my head?” said Jim. He didn't think he'd be able to fall asleep—but he did.

When he woke up Mrs. Jones took the wires off.

“That's all there is to it, Jim,” she said. “You can go home now.”

The next week Jim went back to the doctor again.

The doctor told Jim's father and mother that Jim had epilepsy and that was why he was having the little seizures.

“The EEG test showed us that sometimes some of your brain cells aren't working the right way, Jim,” she said. “So I'm going to give you some medicine that should stop them from doing that.”

Jim started taking the medicine every day. At first he didn't like taking it. He said it made him feel sick to his stomach. But after a little while the sick feeling went away.

The seizures went away, too, and Jim's mother and father were very pleased. Jim started to do better at school, too, and his teacher gave him special work so he would catch up.

Jim was surprised that he had to go on taking the medicine even though he wasn't having any more seizures.

He asked his teacher about it.

“When I had strep throat I took medicine and when it got better I didn't have to take the medicine any more,” he said. “Why do I have to take my epilepsy medicine when I don't have seizures any more and I don't feel sick?”

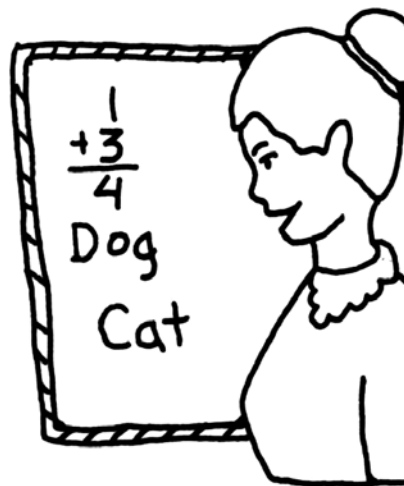
“You’re not taking the medicine because you are sick, Jim,” his teacher said. “You’re taking it to keep seizures from happening.

“Epilepsy is different from a strep throat. A strep throat is an infection that you can catch. But you can’t catch epilepsy. Epilepsy isn’t a disease at all. It’s a word that describes how your brain cells act sometimes.

“The medicine keeps your brain cells working the right way, but if you stopped taking it so there wasn’t enough in your body to do that, your brain cells could start to act up again and you’d probably go back to having little seizures.

“I’ve had epilepsy since I was your age,” his teacher went on. “And I still take my medicine every day. I take it because I don’t want to have any seizures.”

Jim laughed. “If you had seizures in class, we’d act up,” he said.



Then he thought for a minute.

“No,” he said. “I guess we wouldn’t. I’d tell the other kids it was a seizure and you’d be okay in a minute.”

“Well, I’m glad you’d do that, Jim,” his teacher said. “That would certainly be a good thing to do. But I think I’ll keep taking my medicine just the same.”





Sandy's mother has epilepsy

Sandy Richmond is 13. She goes to junior high school. She likes to collect records and go on field trips with her friends from school. Her favorite subject at school is art, and she hopes to be an artist some day.

Sandy doesn't have epilepsy, but her mother does.

When Sandy's mother has a seizure she doesn't fall down and shake, like José. She doesn't stop and stare for a few moments like Jim.

Sandy's mother has a different kind of seizure. It makes her walk around as if she is in a dream.

The extra messages that her brain cells are sending out prevent her from knowing what she is doing during the seizure, and after it is over she doesn't remember what happened.

Sandy's mother always does the same thing during a seizure. First, she seems to be

looking far away. Then she moves her lips as if she is chewing gum. Then she begins to pull at the sleeve of her dress or coat. Then she walks around as if she doesn't know where she is going.

The kind of seizures that Sandy's mother has are called **complex partial** seizures or **psychomotor** seizures or **temporal lobe** seizures.

Sandy was very scared when her mother first started having seizures.

They began a few months after she hurt her head in an automobile accident. Sandy could not understand what was happening. She did not know why her mother was doing such strange things. She did not know why sometimes her mother did not seem to hear her and could not talk to her.

Sandy's father explained it when he and Sandy's mother got back from seeing the doctor.

“The doctor says Mom has epilepsy,” he said. “She has seizures because when she hit



her head in the automobile accident some of her brain cells got hurt. They healed up, but it left a scar, just like a cut leaves a scar when it heals.”

“Why would a scar make Mom do those strange things?” asked Sandy.

“An ordinary scar wouldn’t,” her dad said. “But I guess a scar on your brain is a special kind of scar. Anyway, sometimes the cells in that part of her brain don’t work the way they should, and that’s what causes the seizures that Mom has.”

“Can’t they make the scar go away?” said Sandy.

“The only way to do that would be to have an operation,” her father said. “But the doctor thinks that medicine will stop the seizures from happening.”

“Good,” said Sandy. “I don’t want Mom to have an operation.”

While they were talking, Sandy's mother came into the room.

"Is Dad telling you what the doctor said, Sandy?" she asked.

"Yes," said Sandy. "But it still seems funny to me that you don't know what's happening when you're having a seizure.

"How can you walk around like that and not know?"

"The way the doctor explained it, the mixed up messages from those brain cells get in the way," said her mother. "But I do know when I'm going to have a seizure. I hear a funny kind of noise."

"I didn't hear any noise before you had that seizure in the supermarket," said Sandy.

"Well, the doctor said it's not a real noise, the kind other people can hear. It's really a sound inside my head. It happens because the seizure starts in the hearing part of my brain."



Sandy thought about that for a minute or two.

“You mean, if the seizure was starting in another part of your brain you wouldn’t hear the noise?” she said.

“That’s right,” said her mother. “If it started in the seeing part of my brain things might look different to me. Or I might see something that wasn’t really there. If it started in another part I might have a strange feeling in my stomach. Or things might smell funny to me.

“The doctor said that lots of times people with epilepsy have a special feeling of some kind just before a seizure starts. In a way, I’m glad it happens.”

“You are?” said Sandy. “Why, Mom?”

“Because it gives me time to get away from the stove or to put down something that might get spilled during the seizure.

It's like my own special warning," her mother said.

"Do lots of people get epilepsy from car accidents?" asked Sandy.

"The doctor said it happens quite a lot," said her father. "That's why Mom and I always tell you kids to buckle your seat belts when we're in the car."

"Do kids have that kind of walking around epilepsy, too?" Sandy wanted to know.

"Yes, sometimes," her dad said. "Younger kids and teenagers, too."

"From car accidents?" asked Sandy.

"Not always from car accidents," her father said. "Sometimes from other accidents that gave them a head injury."

"Sometimes it just happens and no one is quite sure why," her mother added.

"You mean kids who have Mom's kind



of epilepsy get up and walk around as if they're asleep during class?" Sandy thought that would seem very strange to the other kids.

"Yes, that can happen," said her mother. "When it does, it's important for the others in the class and for the teacher to know what is happening."

"When you had the seizure at the supermarket I heard one lady say very quietly to her friend that you were probably on drugs," said Sandy. "That made me mad."

"It would have made me mad, too," said her mother, "if I'd heard her. But, you know, if people don't know what epilepsy really is and what is making a seizure happen, they will make up their own reasons."

"Mom," Sandy said. "If we're somewhere like a supermarket or a place where there are lots of people and you have a seizure, what should I do? What do I say? How can I make them understand?"

“We asked the doctor that,” said her father. “I wanted to know, too.”

“The doctor said the best thing was to keep close to Mom, to walk along with her, guide her gently away from anything that could hurt her, and keep talking to her in a quiet voice—not excited or anything. Tell anyone who asks that she’s having a seizure and she’ll be fine in a few minutes.

“So long as we stay calm about it, Sandy, so long as we don’t seem upset, other people won’t be either.”

“Can’t we do anything to make the seizure stop, Mom?” asked Sandy.

“No, Sandy,” her mother answered. “You can’t make any kind of seizure stop, and you don’t have to, because it stops all by itself. That would be true if I had a falling down seizure, too. It would still have to stop by itself. And it would.”



“Do you think you’ll ever have that kind of seizure?” said Sandy.

“No, I don’t think so. The doctor didn’t think I would. I hope the new medicine I’m taking will prevent the kind of seizures that I have now,” said her mother. “If I don’t have any seizures for a year, our state law says I can drive the car again. I can get my driver’s license back.”

“Oh, good,” said Sandy.

“In the meantime, I’m going to make sure I get enough sleep and take my medicine,” her mother added.

“Shall I get your medicine for you now, Mom?” said Sandy. “You could take it with some of that ice cream we just got.”

“No, thank you, Sandy,” her mother laughed. “I just need to take my medicine at the times the doctor said. And I certainly don’t need any ice cream now.”

“Oh,” said Sandy. “Well, do you suppose I could have some?”

“Sure,” said her mother.



Medicines for epilepsy

José, Jim, and Sandy's mother all take medicine to prevent seizures from happening.

They take different kinds of medicine because they have different kinds of seizures. What works for one kind may not work for another kind.

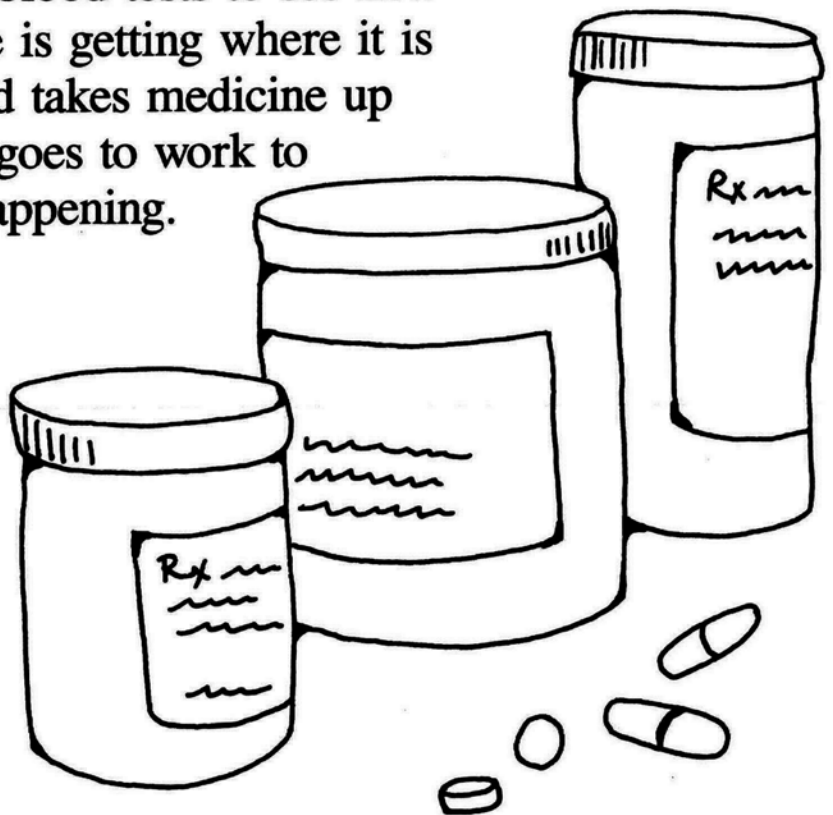
Children learn at school that taking drugs when you don't need them is bad. But taking medicine to prevent seizures is different. Children with epilepsy need the medication, just as other children have to take shots and pills to control allergies or other health conditions.

The first medicine that José got did not do a very good job of preventing his seizures, even though he took it just as the doctor had said. So his doctor gave him a different kind, which is working much better. Lots of people who have epilepsy do not have any seizures if they take their medicine every day, and if the medicine works the way it is supposed to.

Jim's mother helps him count out the right number of pills that he is supposed to take for each week. He reminds her when it is time for him to take them.

Sandy's mother has to take two kinds of pills to prevent her seizures. She is careful to take them at the same time every day. She knows that if she takes too little or too much medicine it will not work well.

Every once in a while José, Jim and Sandy's mother have blood tests to see how much of the medicine is getting where it is supposed to go. Blood takes medicine up to the brain where it goes to work to keep seizures from happening.





Things to remember

A long time ago people didn't understand why other people sometimes had seizures. They saw the seizures, and thought they were very strange. They were scared by them. They didn't know it was all happening because a few brain cells weren't working properly, so they made up their own explanations for what they saw.

Like most made up reasons, these old ideas were very wrong. Today we know better, but if you have epilepsy, or if someone you love has epilepsy, every once in a while you may meet someone who still thinks some of the old, made up ideas are true.

That's why it's important for you to remember:

- Seizures are not caused by any kind of magic or mean spirit.
- Epilepsy is not catching. You cannot get it from someone else, and no one can catch it from you.
- Epilepsy did not happen because of anything bad that you might have done, or that your parents did. It just happened.

- You cannot hurt anyone during a seizure.
- Having epilepsy does not mean that you are crazy.
- Seeing something that is not there, or smelling a strange smell, or hearing a funny noise that no one else is aware of does not mean you are crazy, either. It is part of a seizure. It happens because a few brain cells are sending out too much electricity.
- Having epilepsy does not mean that you are any less intelligent than other people or that you will become less intelligent. Some retarded people have epilepsy, too—but it wasn't the epilepsy that made them retarded.
- You cannot swallow your tongue during a seizure. It is fastened to the bottom of your mouth.
- You should not put anything in the mouth of a person having a seizure. It may hurt his teeth or his jaw.

- Living a normal, active life, playing sports and having a good time will not make you have more seizures.

If you have epilepsy, remember that it is just a part of your life—a few seconds or a few minutes out of all the interesting things you see and do. And the more things you do and interests that you have, the less important epilepsy will seem to be.

Remember, too, that you are not alone. Thousands of children just like you have epilepsy. Thousands of grown ups have had epilepsy when they were young and now have children of their own, interesting jobs, and happy lives.

And you will, too!

