

SPIRIT ROLE-PLAY

Adapted from *The Spirit Catches You and You Fall Down* by Anne Fadiman
Johanna Shapiro, Ph.D.

SETTING: Family conference. Present are **Lia Lee**; **Nao Kao**, Lia's father; **Foua**, Lia's mother; **Neil Ernst**, Lia's family physician; **Effie Bunch** (visiting nurse composite); **Jeanine Hilt** (social worker/psychologist composite); and, toward the end of the interview, Arthur **Kleinman**, psychiatrist/medical anthropologist composite; Bruce Thowpaou **Bliatout**, Hmong medical administrator/elder composite.

TASK: To work out appropriate medication for Lia Lee. At this time, Lia is about 3 years old. She has had many hospitalizations for seizure disorder, sometimes accompanied by fever, pneumonia, and infections of the middle ear. She has also had several episodes of status epilepticus. Both her doctors and her parents are very concerned. She is currently prescribed a very complicated drug regimen, which her mother does not follow.

Caveat: There are no "bad guys" in this role-play; everyone is trying to do his or her best

Neil: I'm glad we've all been able to get together. Now, Mrs. Lee, can you tell me what medications you are currently giving Lia?

Foua: Some red, some white, when she seems sick, if the medicine isn't too strong.

Effie: See, they've got it all wrong. Lia is so spoiled, her parents won't do anything to upset her. I can't believe the amount of time I've spent over at their apartment. I've tried everything – colored stickers, moons for night, suns for morning. I've drawn lines on the medicine droppers to show how high to fill them. I've used a pill box, I've even tried taping Lia's pills to a calendar! It's no use.

Neil: (comfortingly) Well, it certainly sounds like you've tried everything, Effie.

Effie: (muttering) Foua is always changing Lia's medication. Sometimes she only gives a little because she thinks it is too strong. Sometimes, if she thinks the medication is helping, she *doubles* the dose. If Lia seems well, she won't give her *any* medication. Foua doesn't like to give phenobarbital to Lia because it gives her diarrhea. She doesn't like the Dilantin because it makes Lia wild.

Jeanine: (school-marmish voice) Foua thinks the Dilantin *changes Lia's spirit in a bad way*.

Effie: Sometimes I think the whole family should be placed in a psychiatric hospital!

Neil: (placating) I'm sure that won't be necessary. But, unless we get this straightened out, and I mean pronto, I'm prepared to involve Child Protective Services if the parents won't cooperate. Mr. and Mrs. Lee, I know you love Lia, but your inability to administer her medications properly may have serious consequences for her health.

Foua: (aside, to Nao Kao) What is he saying?

Nao Kao (aside, to Foua): He's angry with us about the medicine.

Neil: (to Foua) Where are you running into problems, Mrs. Lee?

Foua and Nao Kao confer.

Nao Kao: (to Foua) Sure, tell him that. Maybe then he won't be mad.

Foua: (hopefully) We give Lia all her medications.

Neil: Mrs. Lee, we know that isn't true, because when we check her blood, the medicines aren't there.

Foua and Nao Kao confer again.

Nao Kao (to Foua): Okay, say that. That is an excuse these doctors like.

Foua: The medicine ran out. We will get more soon.

Neil: (exasperated, he has heard this exchange) Look, Mr. and Mrs. Lee, my job is to control Lia's epilepsy, with the end goal of preventing mental retardation and severe neurological damage. My job is to practice good medicine. It's your job to follow-through with the directions I give you.

Nao Kao and Foua (together): Yes, yes, we follow directions.

Effie: (disgusted) They always *say* yes, but they have absolutely no intention of doing what you want! These people are set in their ways. They are rigid, stubborn and backward. You simply can't get through to them.

Jeanine: (shocked) I couldn't disagree with you more. The Lees are smart, communicative, and energetic. I've never seen parents who love their child more than the Lees. Lia is very special to them, she is like royalty in their eyes.

Effie: (sullenly) Exactly.

Nao Kao: Exactly right (smiles at Jeanine). We do everything for Lia. We spend more than one thousand dollars on herbs for Lia from Thailand. We sacrifice chickens and pigs for Lia. (He pauses, so that everyone present can appreciate the significance of his next statement). I even think about sacrificing a cow for Lia.

Neil: That's very nice, but it's not going to help her. Only the medications, given correctly, absolutely correctly, can help her.

Jeanine: No one could follow this regimen, not even a Harvard graduate. Right now, Lia is supposed to be taking Tegretol, Dilantin, and Phenobarbital, Tylenol and Valium for fever, and Ampicillin if she has an infection, also antihistamines and a bronchodilator. Some of these medications are pills, many look very similar, and others are elixirs. Some of the pills have to be broken in half. Some have to be pulverized and given with food, some are supposed to be given daily, some as needed. Who could keep track of all that?

Neil: (stubbornly) This is the appropriate medical regimen for a kid as sick as Lia is. I refuse to compromise her care and resort to second-class care. Look, Jeanine, I know you're just being culturally sensitive by trying to understand all this business about amulets and animal sacrifices. I know you've spent countless hours out at the Lee's home. But this is about more than just the Lees. I want to show the Hmong community that certain things are just not acceptable medically. I feel it's important for these Hmongs to understand that there are certain elements of medicine that we understand better than they do and that there are certain rules they have to follow with their kids' lives. I want the word to get out to the Hmong community that if they deviate from that, it's not acceptable behavior.

Jeanine: (darkly) If you're not careful, the only word that will go out to the "Hmong community" is that American doctors don't care about Hmong patients and give them bad medicine. Why don't you ask the Lees how they feel about Lia's care so far?

Neil: Fine. I have no problem with that. (To Foua) I hope you understand how much time, effort, and money has been poured into Lia. We haven't skimmed anywhere. She's

been in the ER 11 times so far, even though I keep telling you that you should come to the clinic if you have questions or if Lia is not having a seizure. You've had visiting nurses, a social worker, and the best efforts not only of me, but of my wife, Dr. Philp, who's even smarter than I am (laughs; no one else does). Not to mention all the hardworking residents at KMC. So tell me. How do you feel about Lia's care?

Foua: (says nothing, looks at Nao Kao)

Nao Kao: I am not happy with Lia's care.

Effie: (rolls her eyes; under her breath) These people are so ungrateful!

Nao Kao: (continues) Last time Lia was in the hospital, she was tied to the crib. This seems very cruel to me. Then, when I left the room, no one paid attention to her, and she fell out of bed and bumped her head. Very careless. Another time, the doctors were yelling and screaming, and put a tube down Lia's nose, which made her cry and gag. You hurt Lia and do not seem to care about her.

Foua: (tugs Nao Kao's sleeve and whispers in his ear)

Nao Kao: Another thing. This Western medicine is making Lia sick. It is too strong. We think it is the medicine that makes Lia have seizures and fever.

Neil: That's not correct. Lia is having seizures and fever because you don't give her *enough* medicine, and you don't give it to her the right way!

Foua: (timidly) When we were in the refugee camp in Thailand, we got medicine for Lia just once, injection. That was good medicine. Don't you have medicine like that here?

Neil: (frustrated) That was probably an antibiotic. It had nothing to do with treating her seizures. (He looks around the room in exasperation). Look, Mr. and Mrs. Lee, if you don't administer the medications appropriately, then I can't adjust the levels appropriately. I'm flying in the dark, don't you see? You are tying my hands.

Nao Kao: No! The only person tied down was Lia!

Neil: Oh, for gosh sakes!

Foua: (timidly) We are just upset because Lia is not happy. It makes me sad to give Lia medicines she doesn't like. We love Lia, all we want is to make sure Lia is not unhappy.

Neil: If Lia is dead, it won't matter whether she's happy or unhappy.

There is a shocked silence. Foua bursts into tears.

Nao Kao: (angrily) That is a very bad thing to say. Very unlucky. We are leaving. Come, Foua, let's go. (He starts to leave)

Jeanine: Nao Kao, Foua, please, please don't leave. Wait a minute. Dr. Ernst didn't intend to offend you. (To Neil) The Hmong consider it to be very wrong, almost like a curse, to talk about the possible death of someone who is sick. You need to apologize.

Neil: (after a pause) All right. Mr. and Mrs. Lee, I'm sorry. That's not what I meant to say. I just want to be able to take care of Lia the way I was trained. Let's take a time out. I have to think a minute.

Foua and Nao Kao chat animatedly with Jeanine. Neil and Effie go off to a corner.

Neil: I just don't know where to go. I'm so frustrated I just want to shake the parents till they understand. I feel like I'm banging my head against a wall.

Effie: (sympathetically) It is so exasperating.

Neil: You know, I have nightmares about "the big one." I'm really scared Lia is going to have a huge status epilepticus seizure one day, and that'll be the end of her.

Effie: Everyone is afraid of that. That's why we're trying so hard.

Neil: I just don't get these parents. Don't they love their kid? Nao Kao puts up a stone wall. Sometimes I think he's deliberately lying to me. And Foua is either very stupid or a loonybird. They even missed Lia's last appointment. How could they do something like that?

Effie: (shrugs helplessly) I can't understand it.

Jeanine: (Has come up behind them, with Kleinman and Bliatout) Actually, the explanation's pretty simple. Foua couldn't find Lia's Medi-Cal card, and last time they wouldn't see her at clinic without it. She was afraid she'd be turned away again. (Pauses) Look, Neil, Effie, everyone here cares deeply about Lia. We all want what's best for her. Since we seem to be at an impasse, I've invited two consultants to join us. This is Dr. Arthur Kleinman, a psychiatrist and medical anthropologist from Harvard University. And this, of course, is someone a little closer to home, someone we all know and respect, Bruce Thowpaou Bliatout, the Hmong medical administrator and community leader. There are also other members from the Hmong and the medical communities here to help. Help us out, people. What would you advise?

ARTHUR KLEINMAN (psychiatrist/medical anthropologist composite)

Might suggest questions such as:

- 1) What kind of treatment do you think Lia should receive? What will make her better? What will make her worse?
- 2) What is the most important thing you hope will happen for Lia as a result of this treatment?
- 3) What are you most afraid of about this illness?

BRUCE THOWPAOU BLIATOUT (Hmong medical administrator/wise elder composite)

Can make suggestions such as:

- 1) Talk primarily to Nao Kao as the husband and head of household, and don't undercut his authority;
- 2) Wish the family good things (prosperity and health for all their children; success in their work; happiness in their home);
- 3) Avoid being patronizing, threatening, or critical (stop talking about Child Protective Services and what a bad job the family is doing);
- 4) Avoid blaming the family, and avoid trying to make the Lees feel guilty for Lia's difficulties;
- 5) Enlist the support of community leaders and members of Lee clan (if these individuals support the medication regimen, it will be much more likely that Nao Kao and Foua will agree to follow it);
- 6) Reassure the Lees about limiting blood draws to the absolute minimum and point out that when the medication is better controlled, Lia's blood levels can be checked less frequently);
- 7) Be open to conjoint treatment – welcome shamanic or homeopathic practices that you think won't do harm and might help

