



Lyrica

By: Barbara Hoefler

Betty climbs into bed with her blonde hair in a braid, not looking forward to another night of lying there for hours before she falls asleep. She covers herself with a pink blanket her Mom crocheted, and lays on her stomach, her head turned to one side. As soon as she closes her eyes, the war begins once again— the fight to not think in bed.

Ugh, I just can't sleep. Brain, shut up! Betty checks the clock: 12:30 a.m., already half an hour has gone by. She gets up, puts on her soft bathrobe, and reads an interesting math article. With heavy eyelids, she goes back to bed. While laying on her side and relaxing to a heating pad on her neck, her mind goes, *I have a test this week...I won playing Scrabble*

tonight...ham for dinner was good... Betty gets up again with a tense chest, annoyed that it's already 1:30 a.m. She leans her heavy head on her hands and drinks warm milk at the glass table in the den. After a while, Betty lifts her heavy body off of the couch, and climbs back into bed. *I'm dead-tired.* She finally falls asleep 40 minutes later.

Betty and her Dad patiently wait in her neurologist's office. On the brown desk, is a thick yellow folder with Betty's name on it full of all the epilepsy medications she has been on in the past. Betty drinks peach Snapple to try and stay awake as her eyelids get heavier and heavier. She reads over her list of problems

to tell Dr. Luciano until she hears footsteps quickly getting louder and louder.

Dr. Luciano rushes into his office with a big smile and says, "Hey, how're you doin'?"

As she closes her eyes and leans her head forward, Betty replies, "I still can't sleep at night; I want to get off Topamax."

Dr. Luciano starts to quickly type away. As he keeps typing, he asks, "How've your seizures been?"

Betty takes a sip of Snapple as she searches through her sleepy mind for the right words. "They're getting worse. Every week I have at least 3 seizures, and my Mom and Dad say they're lasting up to 15 minutes now." She takes a deep yawn.

The doctor's smile goes away, and he turns towards Betty. "That doesn't sound good. Seizures longer than 10 minutes can damage the brain, and bad sleep only makes seizures worse. Let's try Lyrica instead of Topamax. It's both an anti-seizure medication, and it helps people sleep."

Betty looks up, making eye contact with the doctor, and says "Sounds good."

After typing away for a few seconds, Dr. Luciano scribbles down the drug name and the dose to take in the morning and night, barely readable. He jumps up from his chair, quickly shakes Betty's hand and says, "Great seein' ya!" as he rushes out the door.

Betty steps off the noisy bus and walks across her shady tree-filled yard to the front door. *Home from college at last. Seems like I was on that darn bus forever.* She turns her key into the doorknob, pushes open the heavy door,

and walks into the den. It has a brick fireplace, a dark brown chair and a long white couch, along with a TV and a backyard patio. *Wait, did I bring my bag inside?* She looks around the room filled with brown walls, then looks toward the floor. *Oh, it's right here.* She walks into the kitchen, a room of 50's fashion with a green counter and medium-brown cabinets. Betty empties her blue lunch bag, and then glances around the ranch-style house.

Betty gets excited as she walks through the house, seeing that nobody's home. She decides to watch TV and walks back into the den. *Wait, why did I come in here? There's the door to the patio, the couch...oh, to watch TV.* She sits on the chair and daydreams for a moment, staring down at the red rug below her. *Maybe I should bike instead. Or should I do homework? Or play the piano?* After staring at the brown wall for a few seconds, she can finally grasp a thought. *Um...I guess I'll do homework since that's most important. I'll need some caffeine to think easier.*

She walks into the kitchen and pauses. *Wait... What did I want to get?* Her mind feels like it's in a deep fog. She closes her eyes, trying hard to think, and soon a feeling inside tells her to open the fridge. *In the fridge there's juice, water, milk...oh, there's iced tea, I'll take that.* Betty rolls her green backpack into the dining room, and sits on her brown, cushioned chair at the wooden table with four flowery placemats. She unzips her backpack and takes out her history and math notebooks, along with the assigned homework.

Betty decided to do her favorite subject first: math. As she takes a sip of iced tea, she thinks, *Okay, question one says, 'What's the product of 28 x 34?'* Betty stares at the wooden bookshelf across the room, daydreaming for 10 seconds. Looking back at the problem to recall the

numbers, she reads: *28 x 34—got it. Okay, 28 x 34 is 30 x 34 minus 2 x 34, which is...um... She looks at the numbers over and over again, then closes her eyes and tries to mentally see the numbers, but all she can see is darkness. After three tries, Betty decides to carefully write out the numbers, as stating each out loud. 1020-68=1020-60-8=960-8=953...I mean 952. FINALLY. Ugh, I miss being a human calculator.*

Betty hears the garage door open in the den. *Oh no—Dad got home, the peace and quiet is over.* Her father walks in wearing a black suit and blue tie, and places his heavy work bag on the beige dining room chair. He has light blue eyes and dark brown hair, along with a happy smile.

"Hey Betty!"

Betty looks up and rubs her eyes after the light blinds her.

"Hi."

"Guess what someone told me at work today?"

"What?" she replies in a low voice, while leaning her head on her hand.

"That you could work as a nursing home aide instead of being a medical data analyst." he says joyfully, as his smile gets bigger.

Betty looks down and stares at the red rug for a moment.

"I love math, and I want to stick to that major. Plus, I'm interested in the...what's the word...medical field after all of my medical problems I've had."

He crosses his arms and says, "I think it's perfect for you!"

Looking away, she can feel her chest tensing up... *Why is he so pushy?*

"I don't know...I'm a little shy."

He puts his hands on his hips, and says, "don't you like helping people?"

"I guess. But number crunching is fun! And medical research is helping people too, using numbers instead of being social." A small smile forms on her face for a few seconds.

"That's true; you've always loved math. But with the problems you've been having mentally, I'm not sure if math is the best for you. Look into it! I think this job would better suit you."

Hmm...maybe he's right? I have to work so hard to use my head on Lyrica.

Unable to decide, Betty looks down and goes, "um...okay."

Dad walks back into the kitchen. Betty looks up the average beginner's payment for being a nursing home aide: \$20,000—and then for a math major: \$40,000. *What?! That's twice the salary of the job Dad mentioned!* Tears fill her eyes. *I'll tell Dad no...um...but it's so hard to think on Lyrica; should I listen to him?* Betty feels stuck between a rock and a hard place. She leans her face in her hands, and cries hard.

I love math class. It's competition day again, me against the calculator.

My high school teacher asks, "What's the square root of 729 minus the square root of 81?"

As students start punching it into their calculators, I immediately say "18."

"How about 57 times 15?"

After two seconds, I go "855," beating the students' calculators again.

Shocked, the students ask, "How do you do that?"

"There's a trick to every calculation. You just have to find the patterns."

Betty stands up and reaches for the ceiling after studying for hours, then walks into the kitchen. *Why did I come in here? Was it for a drink? Oh, I see Mom and Kathy lined up getting dinner; that's right, it's dinner time.* She waits in line to get her meal, behind her sister Kathy. Kathy has short brown hair, long earrings, and just started college towards an accounting degree.

Betty starts to get her dinner. She fills half her plate with green beans, one-fourth with the fried chicken, and the rest with yellow rice. After staring at her white plate full of food for 10 seconds, she thinks, *wait...I took too many green beans; let me put some back, and get some more chicken.* She glances at her plate for another 10 seconds, trying hard to think about how much she wants. *Wait, now I have too much chicken, and a little too much yucky rice.* After putting some of both back and getting more green beans, she looks at her portions, again. She starts to feel hot from the frustration as her Dad walks up behind her.

"Are you almost done? I'm hungry."

"Sorry Dad, it's just so hard to choose."

"Okay, please finish soon."

Dad walks into the den and watches TV for a minute.

Oh, I guess I'll just stick with what I have.

Betty glances at her plate once more.

"Okay Dad, I'm done."

Dad rushes into the kitchen as Betty begins to leave.

"Remember to look into that job I told you about."

Scared to tell him what she found, she replies, "Uh...okay."

Mom, Dad, Kathy and Betty are seated at the wooden dining room table with the chandelier on.

"I got an 80 on my history test today," Kathy says.

That's right, I did good on a test I got back today too! What was it...um...math? Yeah. Betty closes her eyes and covers her ears, trying to ignore everyone around her talking. *What did I get...90? Oh, that's right: 95. How do I say it? I... got...a...90-no, 95...on my...math...what's the word? Homework? No, test. I got a 95 on my math test.* Betty opens her eyes, and waits a minute to speak, repeating the sentence mentally over and over until there's a pause in the conversation.

"I got a...95 on my...math test."

Kathy replies, "We're not talking about tests anymore. You interrupted my soccer game I was talking about!"

Betty's chest tenses with stress. *I hate how it takes forever just to say one sentence! And they don't even care about my grade.*

"My soccer team won five to nothing!"

I have a question coming, I can feel it...come on, words! Betty looks at her meal and thinks hard. *What...state? City? Oh, town...did you p...um... pl...plum? Play? Okay.* Seeming like forever, she repeats the sentence in her head, until silence fills the room. "What town did you play in?"

Dad replies, "Huh? I didn't play today, I worked-in Riverhead, like always. Don't you know that already?"

"I meant...what you guys were-um-talking about before."

Kathy turns to Betty. "What?"

"Your sparks...no, um...sports."

As Kathy rolls her eyes she says, "Oh, in Southampton."

I feel like I have the brain of a 100-year-old.

Tired from studying, Betty drags her feet into the kitchen to do the dishes. "Boom, boom, boom" ...*what is that?* Betty looks towards the den. *Oh, music from Dad blasting his movie like always.* She gathers the plates, pots and pans together. *What else is there?* She looks around the kitchen and collects the cups and plastic containers.

Betty looks at the corner of the counter. *Oh wait, I forgot the...what's the word? Utensils. All set.* Enjoying the warm soapy water, she starts to taste salt in her lower throat. *Uh oh, a seizure could be coming.*

"Dad, please turn down the...um...TV."

"Okay, but I still need to hear it." He turns it down slightly.

Just ignore it, stay focused. Betty scrubs a lunch plate used for spaghetti. *Getting the tomato sauce off this plate takes forever. Oh no, the salty taste is increasing!* Betty's awareness gradually gets worse as her mind begins to feel like she's half asleep.

"Dad, please turn it down more! I...can't...think!"

Similar to when one is dozing off, her focus just about disappears. *Where's...the...dish drain?* She tries to put the plate into the dish-drain, when suddenly, she drops it. The sound of the crash causes Dad to come rushing in. "What happened?" He looks at the floor. "Another plate broken? Please try to be more careful."

Betty just stares straight ahead at the brick wall. She starts to mumble and rub her pointer and middle fingers together on her right hand.

"Oh, I see, you're having another seizure."

Mom rushes in and asks, "What was that crash?"

Dad points to the broken plate on the floor.

"She must have dropped it when her seizure started."

Her parents watch her as she stands, stares, and continues to mumble nonsense. They watch the clock and stand near her to make sure she doesn't fall over. After seven minutes, she stops mumbling, stares 15 more seconds, then starts to look around the room.

Mom asks, "Betty, are you okay? Can you hear me?"

"Um...what?"

"Are you okay?"

"Oh, yeah."

"You just had a seizure." Dad says.

Mom calmly tells her, "Lay down and relax, I'll finish these."

Drowsily, Betty whispers, "Okay. I...can't...think...need to...nap."

"Watch out for those plate pieces."

"Okay."

While Betty holds the counter to balance, mom sweeps the plate pieces out of Betty's walkway. She slowly walks to her bedroom next to the kitchen, lays in her beige bed and falls asleep as Mom cleans up the pieces and finishes the dishes.

About an hour later, Betty's Dad walks into the kitchen and pours out the extra ice from his beer glass. The noise wakes Betty up, but she feels back to normal, mentally. She walks into the kitchen where Dad is refilling his ice-trays and gulps down some apple juice to rehydrate.

He makes a big yawn. With heavy eyes, he asks, "Did you look into going towards a nursing home aide?"

She looks up and down a few times before saying, "Yeah. I love math and research, so I plan to um... stick with that." She tenses up, not looking forward to his reply.

"What's wrong with the job I mentioned?" His face becomes concerned.

"I googled the...um...beginner's pay, and the job you mentioned pays only twice...I mean half of the medical research job." Betty turns away, facing the wall as her eyes begin to tear up. Dad puts his hand on her right shoulder, and she turns around.

"Don't cry. I just want what's best for you, and how you're doing right now doesn't seem so good," he says as he gives Betty a big hug.

"I know, but math is what suits me best." Betty takes in a deep breath as Dad keeps hugging her.

"Okay, just keep the nursing home aide idea in mind, and look into it some more. You might like it more than you think!" He puts his glass near the sink, walks away and says, "I'm going to bed. Goodnight!"

"Goodnight."

Betty closes her eyes and thinks about what her Dad said, along with all the ways that Lyrica is negatively affecting her. *Now I don't know if I'll succeed in the future; I'm scared. If I can't do math, and I can't use my head for anything, then what is there to life?* Betty goes to her room, sits on her bed, and cries until her eyes start burning.

Fifteen minutes later, she quietly sneaks into the kitchen, takes a steak knife from the brown drawer, and puts it against her wrist. Touching a large vein, she pushes hard, back and forth. When it gets close to bleeding, she suddenly remembers

her favorite high school teacher repeating, 'Do your best, do your best...' *Um, maybe there's a way out of this, just do my best.*

The next day, Betty stays home from school, spending hours staring at the wall, as she becomes more and more worn out from crying. At 3 p.m. as Betty finishes her first meal, her mom comes home from work in a striped skirt.

"Betty, I called your neurologist today and told him you had another long seizure. He's concerned, and wants to see you soon, so I made an appointment for next week."

"Okay." Betty's eyes fill with tears.

Mom's eyes quickly widen as she asks, "What's wrong?"

"I wish I didn't have epilepsy! I have nothing good in my...what's the word...future." Betty leans her heavy head on her hands.

Mom lights a lavender candle to help Betty relax, and sits down. With a joyful voice, she says, "Try thinking positive. You're great at math, crocheting, playing the piano, and more!"

Betty cries out, "But you don't understand!" She starts to breathe quickly and heavily.

"What don't I understand?"

Staring at the floor, in a low voice Betty says, "Never mind. No one would understand unless-um-unless they could be put into my body." She starts to cry, hard.

Mom stands up and says, "Come here, sweetie. I love you."

She hugs her for what feels like 15 minutes. Betty's spirits are uplifted and soon she stops crying. She closes her eyes to focus better on what she's trying to say, as she continues to lean her head on Mom's shoulder.

"It's just that I can't use my head anymore from... Neurontin? Topamax? No, Lyrica. I forget what number I'm up to when I try to count my-um-crochet stitches. I can't use my head to calculate. I can't even decide what to do from being so mentally tired all day."

"Let Dr. Luciano know when you see him. Maybe he can put you on a different drug for your seizures."

Betty takes a step back. "Won't he get mad? I've had to get off so many different meds already from the side effects bothering me. Keppra made me behave psychotic, Vimpat-no, Ritalin-made my bone density very low, Tegretol gave me migraines...I could go on forever!" Feeling exhausted, she lays on the couch.

Mom puts her warm hand on Betty's ice-cold hand and says, "He won't get mad. It's his job to not just control your seizures, but also to make sure you're not suffering on the drug you're taking."

Betty closes her eyes for 30 seconds, trying hard to decide.

"Okay, I'll try."

"No one knows how hard it is to live feeling brain-dead!"

6 months on Lyrica, I want to get off. Remember to tell Dr. Luciano to get me off this drug.

Rushing in, the doctor shakes my hand and says, "Hey, how're ya doin'?"

"Okay."

"How've your seizures been?"

"Still once a month."

"How's your sleep?"

"Still hard to sleep."

"Okay, let's increase Lyrica to 200 mg. And keep taking Melatonin."

"Okay."

He starts quickly typing away, and Betty's chest starts to tense up. *Oh, come on, tell him! What do I say? Get me off Lyrica? Can I stop taking Lyrica? What if he gets mad? Should I?*

Very soon, Dr. Luciano quickly gets up. "Okay, great seein' ya! Take care!" He shakes Betty's hand again and rushes out of the room.

Oh, he's too fast for me! I keep missing my chance to put the words together into a full sentence! Creating a sentence is like solving a puzzle. Betty starts to get hot from the rush of emotions; stress, anxiety, sadness, and depression.

In the waiting room, Dad reads the news as Betty sits, nervous about what she's about to say—quickly bouncing her leg up and down. She looks out the window as the morning sun shines on the tall New York City buildings as she keeps trying to decide when to start talking. *The appointment is only a few minutes away; just tell him.*

"Um...Dad, I need to tell you something."

"Hold on, let me finish reading this paragraph." He reads the rest and asks, "What?"

"I want to stop taking Topamax...I mean Lyrica." The room suddenly feels like it's 100 degrees.

"Why?"

"Because it's so hard to think." She closes her eyes and pauses for a moment. "And it's not helping

me at all; I still have many long um...seizures and sleeping is hard still." Tears swell up in her eyes as she starts to sweat.

"Yes, your seizures are only getting worse. But I think it's up to the doctor to decide what to do."

Betty cries out, "No one knows how hard it is to live feeling brain-dead!"

With a confused look in his eyes, he asks, "What do you mean by 'brain-dead'?"

"Lyrica makes me drowsy...all day. The only time it's easy to think is when...there's no distraction: in bed. It's harder to sleep now." Betty takes a long yawn, and leans her head on her hand.

Dad's eyes open wide and his eyebrows go up.

"Really? Why didn't you tell the doctor this? And why didn't you tell me?"

"I've been trying so hard each month to ask Dr. Luciano to get me off Lyrica, but...what was I gonna say? He's too fast for me. Plus, I'm scared that he'll get mad at me for, um, frequently asking to change what drug I take." She starts to shiver from the cool air-conditioning blowing on her wet back.

"Yes, the doctor says it can take many months to get used to a drug and see it's full effect. Let him decide what to do. But don't worry so much; he won't get mad." He rubs her back to help her relax.

"I've been on it for...10 months? No, one year now. Don't you think it's time to try something else?"

"I'm not the doctor, but I guess one year should be enough time. Okay, when we see the doctor today, I'll let him know that you want to stop taking Lyrica, and we'll see what he says."

Betty takes a big sigh of relief, with hope that she may be able to finally stop taking Lyrica.

Coda

I am an epileptic. My seizures began in 1996 at the age of eight. The cause of the seizures is not clear, yet they began soon after my near-death experience of liver failure from Wilson's Disease in December 1995, when I had less than a ten percent chance of surviving without a liver transplant. Growing up after my transplant, I have been prescribed a variety of different epilepsy medications over time, with my complex partial seizures continuing to occur monthly with most of them. But when I turned 17 and I changed from taking Keppra to Topamax, my seizures soon became twice a month, then four times a month, some lasting 15 minutes. I opted for brain surgery in 2008, but that only stopped the seizures for six months—they returned in January of 2009. By then, I had developed insomnia. That autumn, my neurologist prescribed Lyrica, with hopes to both stop my seizures and help me sleep better. The seizures continued to occur once a month, and Lyrica made me so mentally drowsy that the only time I could think without talking my thoughts out was in bed, where it was quiet and dark with my eyes closed. Being so tired all the time, it was hard to put words together fast enough to respond in a regular conversation. After 6 months on Lyrica, deep down I knew I had to stop taking it, for I felt like attempting suicide many times with no hope for my future because of the fear of being a failure in this world. Every month when I saw my neurologist, I wanted to ask him to get me off Lyrica, but I was afraid to ask him, fearing he would get upset. I regretted not asking him to stop Lyrica after I left his office.

Currently, I am a senior at Stony Brook University, majoring in Applied Mathematics and Statistics and minoring in Writing. Luckily, my last seizure was in 2012. That was when I began taking Clonazepam, and my seizures stopped. But unfortunately, beginning in 2009 my brain injury from liver failure (and possibly from brain

surgery) has led to many psychological anxiety issues. These include insomnia, hyperventilating, physical tension, skull pain where the brain surgery was, moments where I feel like I'm living in a memory, and sensitive to fast-paced stress at a job. I have taken control of most of what I listed for the most part, but a few of them still are a big problem for me today.

I want to help people with epilepsy in as many ways as I can. Along with volunteering at Stony Brook Hospital doing research work in the neurology department, I have been fundraising towards a cure for epilepsy. I began this in June 2015, and have now fundraised almost \$31,000.

I want to spread the word on how challenging it can be to have epilepsy. Being an epileptic is not just a seizure here and there; it affects the quality of one's life overall. The medication side effects have a big effect on many people. I have experienced medications that cause migraines, psychotic behavior, facial hair growth, weight loss, clumsiness, and constant drowsiness, just to name a few. And after a seizure, many people like me feel so tired for the rest of the day, unable to do any mental tasks.