Epilogues
2011

a writing collection displaying the talents
of people affected by seizures

EPILEPSY
FOUNDATION®
MINNESOTA
Not another moment lost to seizures™

Our Mission

The Epilepsy Foundation of Minnesota leads the fight to stop seizures, find a cure and overcome the challenges created by epilepsy. Our vision is a world where people with seizures realize their full potential.

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Dear Epilogues Collection Reader,

We are delighted to publish the fifth edition of Epilogues in 2011! This book of written works, including poetry and prose, was compiled by the Epilepsy Foundation of Minnesota (EFMN). The authors are living with epilepsy or have a close relationship to a person with epilepsy.

The Epilogues collection is part of EFMN's larger Creative Arts program, showcasing the creativity and talents of people with seizures and raising epilepsy awareness in our community.

All written works are grouped into three classes by a volunteer committee: Judges' Choice, Superior and Meritorious – in a poetry category and a prose category. Authors were reviewed and ranked based on the committee's understanding of the author's emotional impact, connection to epilepsy and presentation. Although the categories are intended to reflect skill, the committee recognizes that each author's contribution as valuable.

The Foundation extends a special thanks to Jean Manrique, who, with swiftness and thoughtfulness, edited this book.

Background information is provided about each author to give greater understanding and meaning to the works enclosed. Epilogues is organized into two sections, alphabetical by author:

1. Sustaining Ourselves - writings by people with epilepsy
2. Movements of Love - writings by family, friends and caregivers of people with epilepsy.

EFMN congratulates each author, new and repeat entrants, for creating and submitting written works to the Epilogues collection. We wish all involved in Epilogues well - your words not only raise epilepsy awareness, but also connect our community.

The Epilepsy Foundation of Minnesota
and the Creative Arts Committee

Sustaining Ourselves

writings by people with epilepsy

Thoughts…

by Mary E. Blissenbach

I ask you to accept me for who I am.
That means this electricity in my brain.

I know it embarrasses you
and you know you are not at fault,
but please don’t feel that way.

I feel lonely enough as it is,
Yet I put the “happy” face on and say
It doesn’t bother me that you don’t understand.
It really does bother me that you can’t deal with me.

Get over it and Get over yourself!

Stop thinking of yourself and reach out to me when I need you.
The electricity in my brain won’t shock you
or hurt you.

Only your silence will.

Mary E. Blissenbach
Age 33, person with epilepsy

I wrote this poem to express my feelings after my mother refused to visit me in the hospital when I was there for in-depth EEG testing. My mother has a difficult time accepting my epilepsy and at times, her behavior and attitude have hurt me. I try not to let the epilepsy get in the way too much. I have been lucky to find a husband who can support and understand what is going on. I have complex partial seizures. I usually have them 1-3 times per month, even with the medications. I am currently in the process of being evaluated for surgery.

If the Seizure doesn't take it, the Rest will

by Stephanie Chappell

Dedicated to those who made it through the battles of seizures only
to lose life's war during a single Rest that cannot be explained,
treated or prevented.

Seizures are the first minute,
short, predictable in action,
bloody, urine soaked and bruising;

Rest is the long rape of the mind
as it tries to put the pieces back together –
finding the pathway to the leg, the tongue,
the toes, and the tiniest nerve –
making Swiss cheese whole.

It was always hard to tell how much of me I would lose
or when
or if I'd even remember what I had lost after the Rest.

Memory became a thing of the past;
plays went by the wayside after character lines were lost
only hours before a performance,
dreams of the screen and stage followed.

My fingers no longer know music notes on ivory, steel, or wood;
my memory fought hard yet trickled little by little,
instrument by instrument in a gallant fight
through *Rest* after *Rest*.

Another passion left after hanging on
for more than a decade;
that's just something that doesn't need description.
It's a calling for the dedicated –still too tender to touch.
The freedom and independence of driving at 16 left
just months before it was within reach
and became a lifelong fight to attain and retain.
Again and again.

A fight remains between the Rest and Me:
the open road.
seizure take me, open road take me,
Rest, you've taken enough.

Stephanie Chappell
Age 42, person with epilepsy

The period of time directly after a seizure, or postictal, is one of the least understood events surrounding a seizure. Likewise, it's the one part of a seizure I fear the most and have lost the most…my thoughts, my dreams, my memories, my abilities and my friends. I've spent my lifetime silently waiting for the next episode and wondering when my life will be turned upside down by a seizure and the ensuing aftermath including total isolation due to society's inability to accept a single event in a person life for only that, a single event. My seizures are controlled with medication and a vagus nerve stimulator. Side effects, not seizures, are daily occurrences/issues.

Trip to Mars

by Dom Colasanti

Nevada hadn't been on my mind at all. Nevada wasn't even my planned destination. Nevada is one of the places I hope to travel in the future. It is known as the Silver State. It has the largest number of horses in America and over two thousand streams for fishing. Nevada has something called "The Alien Highway." To start my journey home for Thanksgiving break from Landmark College in Vermont, I took a shuttle to Hartford CT International Airport. Everything was going great, chatting with my friend about music and what his plans were for Thanksgiving with the family. He lived in Pittsburgh and was heading home on a different flight than mine. Knowing that I was not the only one from another state made me feel more connected to the community of Putney Vermont where the campus was.

It was just a normal day until halfway through the flight when I decided to take a snooze. I remember the take off runway was 10 and the day was very gloomy for a flight on Northwest Airline before they merged with Delta. Perfect day for a flight and snooze with a light drizzle. That is all I remember until a TSA agent told me that I had a seizure halfway through the flight. The plane landed in Minneapolis International Airport and I was wheeled off of the plane in a wheel chair. All of my important school books were stored in the compartment up above. The TSA did not know that I had carry-on luggage but he did grab my computer bag with my computer. Fewftah… Losing my computer could have been a nightmare with all of my files for class in it.

I have complex partial seizures and grand mal seizures. After my grand mal seizure on the plane I rested up several days at home missing a few classes. I decided to still go back to college after Thanksgiving. But I was nervous about flying back to school alone again so my mom came with me. The bag that the TSA had left on the plane contained all of my notes and books for Research and Analysis, Art History, my school sweatshirt, a Def Leopard CD and a Foo-Fighters CD and even my check book, two bumper stickers I was bringing home for my parents cars. I thought, "I'm f---ed", but glad my seizures did not get any worse. I lost my driver's license for 3 months after and waited all of the months to drive again. I haven't had any grand mal seizures since then and now drive a silverish-blue VW golf, which I named Squeaky Blueberry because of its used squeaky brakes. Area 51 was the last place that my lost luggage was tracked to up until this day. My parents and I have wondered where it is now. Somewhere in The Himalayas probably. LOL.

Area 51 has some rumors that real aliens exist. I never know when I have a seizure. This makes me think epilepsy is like an alien too. Was there something that triggered it all to go wrong on this flight? The airport only has four main gates for planes 1,2,3 and 4, which was all good. Seemed like I found my seat okay, the dude next to me had some kind of caveman game on his iPhone that he told me was called Caveman Crush or something like that.

Losing all of my books is the most I can remember about my seizure on the flight. This summer I have been enjoying volunteering with Three Rivers Parks District. I hope to follow up with my dream career in either wildlife management or even becoming some kind of wildlife journalist for National Geographic someday but who knows if I will even go that far?

My skills have been writing, art, dedication, optimism and trying to live life to the fullest with my complex partial seizures. It has always been my parents, friends or teachers that have known me for awhile that notice when I am having them.

I hate math to the degree that if I could get every book for free I would burn them even though I got through the math classes needed to take biology. If I could describe the flaming flesh of any math book they would smother just like burning charbroiled sausages on a stick over a campfire. I decided to take a semester at Normandale Community College for a change with only two classes on my plate. I was glad to hear that math was not required for biology and creative writing class.

I believe that seizures are a very important part of my life. But I almost forget about them during the day until I have to take my next med between, breakfast, lunch and dinner. The seizures that I have make me try harder at whatever I am doing for class or work. I can do this. Basically when I have small seizures I do not notice but my parents do. I always have wondered if people living without seizures can detect seizures in others. I kind of try to forget my seizures because I had them since 6th grade and live with them up till this day. If I didn't have them I think my life would for sure be less interesting. Some of the ways my life would be different include: no seizures, different personality, wouldn't be able to meet people with seizures no Epilepsy Foundation of Minnesota or doctors to let me know what has been going on in my head through all of these years. In a way that is how seizures are my strength that seems to be decreasing each day, which is good I think. I haven't let them get in the way of my life, education, personality, optimism or dedication in any way.

In one of my classes I compared my life with seizures to Helen Keller's blindness. I never knew I had a disability until my doctor told me. In some ways I could be like Helen Keller. We are both human beings. We both have a disability. With help from a teacher in school and a therapist to help talk about my learning disability, I was challenged to do the blindness experiment. I have had a lot of help throughout the years with an alien disability. We had to imagine ourselves in Helen Keller's shoes. This task proved to me that no matter if you have a disability or not you can still a good life and be successful. I guess you could say seizures can make people see the world even better.

I still have never been to Nevada. Or maybe I have? How weird that my luggage ended up in Area 51. IS THIS A SIGN?

Dom Colasanti
Age 21, person with epilepsy

My inspiration for this written work was EFMN, my mother and me because I have enjoyed creative writing my entire life. I am currently taking a creative writing class at Normandale College and plan to take a poetry class next fall. My seizures and epilepsy have affected my life by making me want to work even harder at work, live life to the fullest and have more faith in everything I do saying, “ I can do this” without giving up. I have tonic clonic and partial seizures. I don’t let my seizures get in the way of my life and some days forget that I have them and go on with the daily medication routine.

Missing Pieces

by Molly Cooney

"I thought about how a part of a living thing can go on without the whole body, not giving up, as if it were waiting for the rest of itself to come back together again."   - Gretchen Legler

It was the twenty-fourth day of rain. The Arctic wind slapped our cheeks and burned our fingers raw; we paddled anyway. That morning the Back River narrowed, and the flow quickened and Laura, Anne, and I staggered our canoes down the river, pulling in sync with our bow paddlers, our knees braced. We shot the first rapid and pulled off to scout the next set of churning waves. The driest line was river left, and we ferried into position and took it. One canoe. Then the second and third. For four hours we continued the pattern. Scout. Shoot. Scout. Portage. Shoot.

Sliding into an eddy on river right, we took a break.

"My knees kill," Maggie said from Anne's bow. "Can we rest a while?"

Anne groaned. "We're three days behind. Suck it up."

"Come on guys, we've got a long day," Laura said. "Pull it together."

Because it was Laura, the girls listened. With her solid legs wrapped in carharts, Laura is gently relentless whether pitching a tent, portaging a pack or settling an argument. The softness of her eyes and the quiet hold of her small hands when we hug communicate a silent steadiness. At eighteen, she already knows how important patience and persistence can be, especially out here in the wilderness where every decision straddles disaster. The girls depend on her intensity and her compassion.

Sagging with exhaustion, Maggie trailed her fingers in the water while Bonnie leaned on the packs and Laura stretched her arms and arched her back, twisting side to side. Watching Anne scour the map, I wondered how long the girls could sustain this pace. Carolyn sat in my bow with her eyes fixed on the swishing water. She hadn't said a word in hours.

I thought of Carolyn getting the call telling her that her brother had been killed. He was an investment banker in London on vacation in the States; she was paddling the Range River in Minnesota. The cell phone call came at dusk. "Your brother was murdered."

"We kept getting disconnected. And there was that weird echo you can get with remote cell phone calls," Carolyn told us one night as we ate beans and rice. "I couldn't breathe."

We were six paddlers winding through the barren lands of the Canadian Arctic from the summer solstice to the early days of August - Laura, Anne, Maggie, Bonnie, Carolyn and I. The girls trained for years, returning to camp every summer for longer, more intensive whitewater trips, preparing to spend this summer before college above 66 1/2 degrees north. I led river trips for years, honing my skills and dreaming about the Arctic.

Finally here we were, hundreds of miles north of tree line with no tall trunks to disrupt the endless horizon, traveling the land where rivers roiled and the ground barely thawed, where our three canoes carried all we needed for forty-five days, where each day we woke, loaded our boats and pushed off to paddle fourteen hours until we camped again. Six hundred miles, no towns, no people, no resupply.

The next morning fog dripped off our paddles as if it were rain. The river spread wide before us and rocks—small as sik siks, large as caribou—formed the left bank as it climbed gently out of the water, extending into tufts of knotty grass and bunches of blue arctic lupine. On the right a pingo bulged like a swollen belly. The sky was steely, the water thick and dark.

We passed the morning quietly, the sun slowly burning through the haze. Our muscles shouted at us as we pushed along, shoulders tight, hips achy, legs bruised and tender. The water chugged six miles an hour and we paused to snack on apricots before the river got too wild.

Rubbing her shoulders Laura asked me, “What was it like after your first seizure?”

“I felt like it wasn’t even my body,” I said. “So many tests and doctors and hospital visits that I hardly had time to teach. And all I could think about was the Arctic.”

“Does it feel real yet?” Carolyn asked. “I mean, do you believe it?”

“No,” I said, knowing we weren’t talking only about my seizures. “I guess it’ll take years. Or maybe never. It’s like rewriting your life.”

“What would happen if you had a seizure out here?” Anne asked, unfastening and refastening the Velcro cuff of her raincoat.

I held that fear so closely I could feel myself being airlifted out, a new leader flying in to finish the river with the girls. I’d thought of every scenario, the details painted clearly in my mind: a seizure in the night, the radio message to a plane, the pick-up from the airport.

“Would we evacuate you?” Laura asked.

“Depends,” I said. “On a lot of things.”

Laura nodded. Anne stiffened. I stared at the rocks passing quickly underneath us, their colors mixing together, swirling maroon and gray, blending black and pink and white in a collage of blurred images draped in light.

“What if we had to evac someone else?” Maggie said.

I worried every day that I’d have to fly one of the girls out with a deep gash, a broken bone or a high fever. Swamped with codeine, she’d watch us stuff her sleeping bag and clothes into a pack, lay her rubber boots on top and buckle it, then we’d gather gear to fill another pack: a bowl and spoon, blue tarp, maybe some sausage, peanut butter, her life jacket. We’d send the heavy things, every ounce of extra weight, then replan our menu for only five people and move sluggishly down the river crowded into two canoes. Five people missing a part of the body they’d begun with. Five people sleeping in yellow tents as if the other body were still there.

“For reals. What would we do if you had a seizure?” Anne asked.
The girls stared at me. I shrugged. These were unanswerable questions until the moment came, if the moment came.

“There’s no easy answer,” I said. “You know first aid. You have the satellite phone. Honestly, there isn’t much else. The rest is just instinct and good judgment,” I said.

Laura nodded.

“Let’s hit it,” I said.

We paddled toward the soggy landing to start our three-mile portage overland to avoid the sharp bend in the river and bypass the U of roiling water that plunged over Sinclair Falls.

As we unloaded the canoes I said, “We’re looking at three trips to get everything over.”

“At three miles a pop,” Anne calculated, “we’ll walk fifteen miles, nine of them loaded.”

“All this to avoid a few rapids?” Maggie asked.

“And a waterfall,” Anne said sharply.

Unfolding the map, I saw the contour lines stretching far apart for most of the portage, reaching like an open hand, fingers spread wide. But at the beginning the lines huddled together, almost touching, shouting of hills and cliffs, and I translated the topographical lines into eskers and ditches created by glaciers scraping over the land, carving drumlins and terraces, the wind sculpting the till like a potter shaping clay. Initially we’d follow the shore just below the tight contour lines, skirting the steep slices in the land, then set out across the flats, scooping around swampy patches and boulder peaks until we hit the cliffs above the water on the other side.

“My stomach hurts,” Laura said quietly.

I glanced at her.

“Just a little.”

“Do you feel sick?” I asked.

She waved her hand. “Not really. I’ll get some Pepto-Bismol.”

With three canoes weighing eighty-five pounds each, seven ninety-pound food packs and six eighty-pound personal packs full of clothes, plus a daypack, two tents, five fuel cans, two camera bags, plus three throw bags, twelve paddles and an unwieldy boot bag, we were in for at least a day of overland travel. We’d walk all night if necessary, following the sun as it followed the horizon, barely dipping below the land at midnight, never darkening the sky as it rode the hills huge and full, burning gold, then orange and pink, then gold again.

“Two canoes first load,” I said. “People with personal packs as support.”

“And two food packs,” Anne added.

“We’ll get everything else in the next two loads,” I said.

We took final sips of water and, with high fives and cheers, loaded up. Anne and I shouldered canoes and the other girls strained into packs.

We followed the shore for a mile, past the calm water and into the raging section of the river. My feet moved quickly, instinctively, along the shore that slanted severely into the rushing water. A one hundred foot tall esker, a mound of sand and rock hardened by thousands of years of freezing and thawing and icy wind, rose abruptly toward the sky. Intermittent sand streams poured down the slope and piled under boulders, shifting them and tumbling them into the water. I didn’t know which rocks would wobble and which would hold my weight, but I did know that my small feet could trigger a landslide of huge rocks. I scooted from boulder to boulder, steadying my stance before moving, nudging each rock before I gave it my weight plus the eighty-five pounds on my shoulders. My damp boots left a trail of footprints, dark silhouettes on the sun-bleached rocks like words across a page. The water whipped by, just a few feet away, foaming over rocks.

When I stepped onto a boulder big as a bear, it wobbled, and I flashed with heat as I fought to regain my balance. Once stable, I looked back at the girls. I watched Carolyn struggle, hunched under the weight, compressed by the pressure like sandstone under granite and I thought about how each decision affects our lives wholly and entirely. To fall on a loose rock could change my life forever—break my femur, crush a rib, or tumble me into the water, sucked under, head slammed on a rock. Wham. Or just twist an ankle. My ankle would heal but delay us enough to miss our plane. Each step was intentional, precise, and I linked them like a writer placing words in sentences and paragraphs that move the story toward an end. And these were tiny moves, only steps of my feet. We rarely think so small-scale. We consider the impact of choosing a job, a city, a partner, but we pass the little moments without hesitation. We have to. And often the little moments are the defining moments, the defining decisions.

Perhaps if Carolyn's brother hadn't gone to the bar that night, I thought. Carolyn must have thought that a thousand times, willing her brother back to life. Sweat dripped down my back, behind my knees and pooled in the curve of my ankles.

When I started anti-seizure medication, I hardly thought about how they might help me. I could only imagine popping pills my entire life, the side effects haunting me every day. To control my seizures the medication would suppress my central nervous system, exhaust me and steal my sharpness. I'd forget things. Lose coordination and be struck by dizzy spells. My metabolism would slow and my food preferences change. I'd gain weight and bloat from retained water. Eventually my teeth would soften, my gums recede, and my facial hair darken. I wondered if the medication would change my personality. But the pills had been my only hope of coming on the trip, so I'd swallowed them and cried.

Cresting a small incline, I surveyed miles of land drowned in bog. My breath came hard and fast as the wind rushed over the land, catching my canoe and trying to spin me around like a helicopter blade. I braced with my entire body against the gusts, wedging my boots between bulges of grass and sinking into the slop.

Anne slipped and twisted to the ground. Laura ran to help her up, and Anne stood smeared in mud and giggling with relief.
"Let's take a breather," I said. "A few peanuts wouldn't hurt."

We dug the snacks out and passed them around. The wind dried my sweat. Laura sat with her arms folded across her stomach.

Someone watching us from above, the six of us weaving around boulder fields and sunken ponds, would see esses sweeping across the barren land like the sketched outline of a landscape before an artist adds paint, long strokes lacing in and out of one another, trailing into a thin line. Backtrack. Then tracing another path, arcing, overlapping the last one, barely moving forward. The observer would laugh at our confused, seemingly directionless travel. We were moving toward a goal we couldn't see, had never seen, and would know only once we got there. We had to trust the process, linking steps to make miles as a musician links notes, trusting they'll flow into a song. From above, the path would seem obvious and our labor exaggerated, but down here, picking across unknown terrain, the girls and I couldn't be sure we'd ever see the end. We could only see our feet and the tracks we left behind us. We kept walking.

Carolyn's crinkled forehead communicated fierce concentration. She knew she couldn't get hurt; her mother couldn't handle another call.

Five hours passed before we arrived at the falls. One trip done, two to go. We turned back and slogged toward the start of the portage. Laura's face was slightly green.

"You're sick."

"How much farther?" she asked.

"Is it only your stomach?" I said. "Are you feverish?"

"My shit was black." She managed a weak smile. "And I'm not shitting you."

I stopped.

"What does it mean?" she asked.

"Diarrhea?" I asked.

A nod. "Lots of it."

I had some medical training as a wilderness first responder, so I knew black shit could mean internal bleeding and abdominal pain was either fatally serious or not cause for worry—there was no middle ground. I knew I had about twenty-four hours if it was serious. But without x-rays or blood tests it's next to impossible to know what's really going on. I didn't know what to do, and I didn't know what to tell Laura.

"You wait here," I said plainly, hiding my panic. "You and Carolyn. The rest of us will get the second load and be back in an hour."

When she didn't argue, I almost cried.
To lose Laura from this trip would be to lose the heart of our group, the slow, steady beating, quiet and constant, keeping our rhythm. The girls knew it, and Laura's pain terrified them. I could see it in the way they looked at each other, sideways and lingering. I could feel it in their heavy steps. I could hear it between their words.

The four of us reached the beginning of the portage and loaded up, nearly folding under the extra weight as we walked back toward Laura and Carolyn. My back was stiff with stress and the pack straps chafed my shoulders.

Stress can trigger seizures; so can exhaustion. We were 12 brutal hours into our day after having slept only five hours, skipping dinner to get even that far and now Laura was really sick. My stomach tightened as the wind dried my tears, pulling the skin taut across my cheeks.

As we approached the waiting girls, Carolyn stared at me, twisting her hair. She knew how easily reality shatters and how nearly impossible it is to piece back together again.

We helped Laura walk slowly to the end of the portage, her steps wide and deliberate. Reaching Sinclair Falls, we slumped into tents without dinner once again. I piled first aid books on my sleeping bag and sifted through them, scouring wilderness medicine manuals by NOLS and Outward Bound. Gastroenteritis, appendicitis, pancreatitis all had rapid onset. All involved cramping. They all involved diarrhea. Gastroenteritis would pass with time, but the other two would worsen and could be fatal. In Medicine for Mountaineering I read that pain that lasts more than six hours or is so severe that it prevents the person from sleeping suggests a condition requiring surgery. Laura slept, her breathing sharp and shallow. It had been thirteen hours since she'd taken the Pepto-Bismol.

I looked at her face, soft, pale and trusting and I cringed. After a few restless hours I walked to the cliff and read more, listening to the water echo off the jagged canyon walls as it raged over the fall.

So often we walk in pieces, our heads in one place, our hearts left back years ago when we lost something, someone we loved deeply. So we continue on, struggling to be satisfied with the pieces we bring with us. What else is there? We wonder. What else can we do but keep going, glad for the pieces we still carry.

But we often carry too much. When we lose something irreplaceable, we compensate by collecting other things: dried flowers, old letters, trinkets. All the extra stuff we drag with us for years, the accumulation of useless things. Out here we have to survive with so little: just enough food, an extra shirt, a few shared books. Out here we have only each other and everything is useful. Life distills into the essential. But whether in the excess of city life or the simplicity of the backcountry, I'm always missing something. I'm always missing a part of my brain.

If you asked me how my brain works, I might say, "Not very well, thank you." Or I might talk of sclerosis, temporal horns and the hippocampus. Or I might not remember those fancier words because the first answer is the truth.

It wasn't always that way. I used to have a solid mind that justified the space the gray matter occupied. I could recite poetry I'd memorized years earlier and cook without putting the frying pan in the refrigerator, the milk in the cupboard. All that changed when my brain misfired during the night and my body seized, my brain struggling to reroute electrical impulses, to start my breathing again.

My brain had actually started to seize several months before that night small lapses, barely perceptible, eroding my memory pebble by pebble. I joked about it at first, thinking I was just getting lazy, letting my brain relax too much. Then I'd had the grand mal seizure. Hundreds of smaller seizures followed, interrupting the electrical flow through my brain, tangling my thoughts and poking holes in my memory. Then the gaps began to fill with childhood moments.

My 6th grade teacher shifted into my college classroom and the family dog I never knew bit me instead of my older sister. I was convinced that a friend had a kidney transplant rather than a tonsillectomy. Or was it her friend that had the surgery? To me the images and stories were accurate, the timelines precise. My memories were visceral. I could map it all out, the way my mind held memories, the way my memories moved. I believed and often still believe that what I remember was true, despite collective family stories and pictures telling me otherwise.

My brain connections became erratic, spontaneous. I'd be teaching and a sudden heat would rush up my legs and hollow my stomach, then my mind would yank me back to five years old when I was waiting at Groveland playground for my mom to pick me up from gymnastics. My purple leotard stretched over my belly and white tights reached for the cement as I leaned against the railing at the top of the stairs. As an adult in my twenties, I fully relived that five-year-old moment. Then I'd be teaching again.

The doctors called them déjà vu seizures. My brain dragged me back to that same scene again and again. The seizures knocked me down, my mind swimming with a gush of memories as I lay on the floor like a fish in the bottom of a boat.

My melting memory slouches the truth to the left, and sometimes to the right, making it seem impossible for stories of my past to accurately sidle up to the present moment. So I stumble through the tangle of facts and into images of deep emotional truth. My story becomes not the claim of recounting the past as it precisely unfolded, but of letting the story lead me, lead us, through the mind with all its necessary- intentional or not- adjustments

In the photo album of my mind, the captions wander. Remembering has become storytelling, an intimate kind of reframing that continues constantly in my head and changes the chapters with every narration. When telling my past, I whisper careful lies between each word, between each breath.

Now I carry paper to write down everything as it comes to mind, as it's told to me. If a friend starts a story and my face stays blank, she gives me more details until it registers and my shoulders relax. My memories stay memories only if I write them down.

We do manage without pieces of ourselves, but we always hope those pieces will come back.

"Molly! She's barfing."

I came back to our campsite. Laura lay halfway out of the tent with her cheek pressed into the grainy reindeer lichen, and I watched her breathing, quick but consistent.

I helped her onto the sleeping bag, and curling around herself, Laura told me that the stomach pains had intensified, cramping below her ribs a little to the left. Stomach? I wondered. Intestines? Pancreas? The night before I'd read that appendix pain can phantom itself into atypical areas, but rarely. I laid Laura on her back and touched the tender spot. She winced. "Describe the pain. What does it feel like?"

Laura grimaced. "Churning," she said. "The cramps intensify and subside, but the churning is always there."

I pushed again, sinking my fingers into her tight belly, and let go. Her face went white.

"Does it hurt more when I release?" I asked.

She stared at me.

Backcountry Medicine said that rebound pain, increased pain on release of pressure, often signaled a serious condition, often meant internal bleeding. I swallowed hard. I monitored Laura's vital signs by taking her pulse, counting her breathing rate and testing for pain every half hour. Her fever was 99.9 degrees. I moved the satellite phone into the tent.

Laura began moaning eighteen hours after her first pain, and with her legs curled tightly to her chest, she stammered, "Don't send me out."

Walking to the water, I found Carolyn on a smooth rock by the falls, an extension of bedrock, an exposed piece of the Precambrian shield, the oldest rock on earth. Across the river two musk oxen roamed the banks as if the Ice Age had never ended, and while I watched them lumber and graze with their tangled, brown hair draping, brushing the land, I thought about the timelessness of this place, how years are swallowed into years without dramatic change. Like art, Arctic beauty endures for centuries, offering glimpses of the past. I slid down by Carolyn.

"How's Laura?" she asked without looking at me.

"How are you?" I asked sliding down next to her.

"When I was five, my brother was nine. He'd bounce me on the trampoline. I'd tuck in a ball, lurching in the air when he jumped." Tears smeared her cheeks. "He had a dumb laugh. Too loud. And he snorted. One time he bounced off the tramp and cracked his head. Seventeen stitches. I brought him to kindergarten for show-and-tell." We sat side-by-side, barely touching.

"I don't believe he's really gone," she said. "I mean, forever."

Wispy clouds streaked the sky shades of lavender and pink, and the hazy sunlight draped the hills like an impressionist painting. I began to wonder if patience could bring all missing pieces back: maybe not exactly what was lost but something to fill the void.

I looked at Carolyn's rounded shoulders, her thick hand tracing through the water like a painter stirring paint, mixing colors, trying to find the perfect shade of blue. Her jaw was tight, grief chiseled in her face.

I imagined her ten years from now, sitting on a park bench watching her son play. Perhaps the way his tiny fingers curved or the knob of his chin would remind her of her brother. Perhaps her son would have the same coarse hair. Or maybe not. Maybe the part of her heart that broke off when her brother died would never come back and she'd just live without it, her awareness of the gap decreasing every day.

I thought about the gaps in my memory and about the space in my enlarged left temporal horn. I thought of how my brain displaced memories, perhaps trying to fill those gaps. Perhaps the déjà vu seizures were my brain's attempt to bring back missing memories. Then I imagined the seizure-induced scars embedded on my hippocampus, rifts widening with each piece of tissue piled on the washboard surface. Maybe not all missing pieces should be brought back.

Sadness washed over me, seeping into my skin, spreading like watercolor over paper. Laura, I thought. *What will we do without Laura?* The clouds withheld their rain and the soft gray sky settled on us like a blanket. The slight swish of Carolyn's fingers through water.

"I didn't cry when my brother died," Carolyn said.

She stared at the water. I held my breath.

"It wasn't until I saw my mom sitting on the couch like she was waiting for him to come home on Friday night," she said. "I'd never noticed how gray her hair was or the way the skin on her hands bunched and sagged." Carolyn looked at the sky. "Her veins were just so blue."

Molly Cooney
Age 37, person with epilepsy

Writing is part of what defines my life. That and dark chocolate. I am currently working on a memoir about solo-leading five teenage girls on a 45-day whitewater canoe trip in the Canadian Arctic. I was diagnosed with epilepsy a year and five months before the trip. "Missing Pieces" is an excerpt from the memoir.

My Real Education

by Lisa DeBord

I always felt like I was a failure, even when I applied myself to the best of my ability. Even then I only got C's and D's. I kept going to school just, barely passing. Kids used to make fun of me because I wasn't as well off as they were. That brought down my self-esteem to the point where I was starting to not care about school or anything else for that matter. I was a slow learner. I had to be in one of those special needs classes.

I finally quit school in the 10th grade. I was sixteen years old. Back around 1987, it was supposed to be cool to quit school. I was drinking, smoking weed, and getting into trouble all the time. I wanted to be part of the crowd. I didn't want to be alone anymore.

I ended up running away from home and was on the streets at the age of sixteen. I didn't know anything about the streets. Two guys that I thought were real nice offered me a place to stay. They said, "We won't let anyone hurt you." They ended up being very mean guys. They told me they would take care of me but they didn't. That was a very bad situation I put myself into. They made me smoke crack and work the streets to support their habits.

One day I was out there on the streets working and accidentally got into an undercover cop car and he arrested me. I finally was able to get away from those mean guys because of that.

I ended up going to juvenile detention. The judge ordered me to a treatment program called Teen Challenge. While I was there, I started studying for my GED, but I finished treatment and ended up relapsing a couple of months later. This has been a pattern for me all my life, in and out of treatment programs trying to succeed.

One day I got arrested again, which was approximately back in 2000. I had to go to the workhouse for six months. While I was there, they said I could use this time to get my GED, so one day I decided that's what I wanted to do, so I did. That was one of the proudest moments in my life. They took a picture of me in a black cap and gown. I never thought for one moment that day would come. I feel this way because I had never completed or accomplished anything before in my life and now I finally had and it made me proud.

In 2002, I decided I would try to go to college. I wanted it so badly, but I was scared. I didn't know much about Minneapolis Community and Technical College back then. I didn't know about the help they offered or about the learning center or anything. I didn't even know about the Pell Grants. Well, I only ended up going for the first three weeks until I got my check and then I relapsed again and ended up quitting school. I thought I was going to be failure and I wasn't ready to stop using crack. I also felt that I wasn't mentally stable.

I ended up back on the streets using and prostituting just like I was doing before. There I was back in jail again.

When I went back to jail in about 2004, I had a seizure. The seizure caused me to fall over and hit my head on the cement floor. Because of that, it busted my head open causing me to have a traumatic brain injury. The officers had just brought us lunch right before this happened and we had fruit punch to drink with our lunch. I was already under supervision because I was having a lot of seizures. The guard had walked by me and saw me lying on the floor and he thought I had just spilled fruit punch all over myself and I was sleep. I hadn't even touched my fruit punch or my food. Who knows how long I was lying there before the ambulance came. The guard kept saying, "I'm so sorry Lisa, I'm so sorry." I think he was afraid that I was going to sue them. I couldn't even remember my name or who the president was at that time. I still struggle every day trying to remember things. When I got out, I had my own apartment from 2009 to 2010. That was my apartment I paid rent for. I had never been independent before.

Still, people would come over all hours of the night knocking at my window wanting to come in and get high, even my daughter. Here I am getting high with my daughter while she's pregnant with my granddaughter. My daughter was 20 years old then. What kind of mother gets high with her daughter?

This was the turning point for me. I couldn't do it anymore. I put myself in a treatment program called North West Residence and graduated from there in August 2010.

I moved from there into an assisted living program that I like very much. While I have been here, I've set some goals for myself and one of those goals was to go back to school. I want so badly to have an education and to be able to have a job that I really like or that I know I will be good at. Sometimes I feel like that won't happen. All my life I have been a failure at everything I've tried to do.

Now there's no stopping me. I get up every morning at 4:00 am and do my homework. Then I leave on the Metro Mobility bus and go to Minneapolis Community Technical College where I now attend school. I'm one of those students that's so determined to pass that I'm always on time for class and I never miss a day no matter what.

◆ ◆ ◆

Lisa DeBord
Age 40, person with epilepsy

My inspiration for writing this is my being able to be in school now and being able to accomplish the things and thought I couldn't accomplish. My seizures have affected my everyday living, far as school is concerned because I have seizures while I am in class and also right before class. It affects my thinking because after a seizure I don't remember anything that has happened. My seizure diagnosis is grand mal seizures and petit mal.

Eviction

by Sarah DuCloux-Potter

Dear Disruption,
I would beg
Of you
To tame
Your tantrum;
To ease your
Pounding
On my
Cerebellum;
To stop
The
Malarkey
Within my
Temporal
Lobe.
Your
Anarchy
Is not
Amusing.
I
Find it
Quite
The
Nuisance;
An
Inconvenience
To be
Sure.
Please play
Somewhere
Else
And
Let me
Rest.
Thanks-
Sincerely,
Me.

Hero

Everything
is just out of reach
so close
so far
until I break
free
and
take hold
of my own
destiny
I
am
my
own
hero.

Unbreakable

Alone
Standing
Amidst the rubble
Of the construction
Outside
Slight.
Frail.
Will it survive?
Yellow tape
Do not enter
Caution!
Rocks piled high
Around.
Swaying
Leaning
Bending
Shaking
But not quite
Breaking.
Maybe it's
Not as
Fragile
As
It
Looks.

* * *

Sarah DuCloux-Potter
Age 32, person with epilepsy

I can honestly say that other than not being able to drive (which sucks!) and the occasional bad after affect, seizures don't affect me at all. If anything now it's a more positive affect as I've gotten to meet cool people at the Epilepsy Foundation and I've had the opportunity to tell people that having epilepsy doesn't have to rule your world - you can still have the most awesome life ever. My life is full and happy; epilepsy takes a very back seat in it. At home I have a cool preschool-teaching husband, a teenage daughter who can run like the wind (or faster) and a cat who keeps us all laughing. I work full time at a job I enjoy and keep active by running. I am really blessed.

Shut Down: A life with seizures

by Kelsie Johnson

Each time they happen,
I feel shut down,
as if all my senses have been
set in the off position.
I stand waiting,
simply waiting,
for it is all I can do
until they pass.
But once they do,
I still feel . . . off,
not quite on the right channel,
blurry and incomprehensive.
And oh how the people stare!
They try and make out
what exactly is going on,
what exactly is going wrong.
I wonder that as well.
Am I helpless?
Am I alone?
Can you hear me?
. . .
Then suddenly,
I am brought back to reality.
Unharmed.
Unchanged.
All is well.
I inhale and tell myself,
“They are not in control.”
I exhale,
blowing away the stress,
the confusion,
the frustration.
I will not be defeated.
They are a part of me,
but they do not define me.
I will keep calm
and carry on.
What can’t kill me
will only make me stronger.
I will conquer,
I will survive
and I will thrive!

* * *

Kelsie Johnson
Age 21, person with epilepsy

I was inspired to write this poem in an effort to help those that don’t live with epilepsy understand what it may be like. It’s been a struggle, since I also have non-epileptic psychogenic seizures that cannot be controlled by medication. The only way to gain control of them is through therapy. There are days I feel very alone with what I have but I have an amazing family, friends and professors who have my back. I have had epilepsy since 2007 and seizures dating back to 2001. I want to share with the world that I have epilepsy but it does not have me.

Officially

by Tayler Johnson

Officially,
it’s been two years.
Two years of no big ones.

Yet the little ones
still linger,
causing me grief.

Officially,
I’ve hit one mile stone,
time to hit a few more.

Officially,
I’m going for a life time.

Tayler Johnson
Age 17, person with epilepsy

My inspiration is my own experience with living with epilepsy. My life has changed since being diagnosed, but I have remained positive with it all. I have grand mal and absence seizures.

Dating

by L.E. LaRue

Sometimes I am still surprised as what can happen in my life from one year to the next. I've been dating somebody for nearly a year now. Yes, me! Who could have thought it was possible? Especially when my relationships failed so quickly in the past.

It hasn't been easy; I will be the first to admit it. I guess I had to ignore my horrible track record and just keep trying. I met her through online dating, the way many couples meet in this day and age. I needed some patience to get there, as it took 2 years and 4,000 matches to find her. I met less than one percent of these matches and most of them fizzled out quickly, often after one date. It was brave of me to tell two of them about having epilepsy, though I didn't get the supportive response I had hoped for. I wondered if I had shared it too soon. In the back of my mind I thought it might have been, at least in part, why it didn't pan out. Sometimes the truth is too ugly to hear. It seemed to remind me why I didn't date for a while, back in high school and college. I just dreaded having to tell anyone about it. I didn't have to share it as long as I didn't date. I was a different person then, I felt lost and had huge self-esteem problems then.

The memory is a vivid one when I told my current girlfriend about the disorder. I was taking off a shirt and she saw my undershirt from Camp Oz. She asked what it was. I knew I didn't have to tell her the whole story but I did anyway. I could have just left it at having volunteered there, which I had done last year. But it would have been hard to keep 'the secret' and I didn't want it to consume me. It seemed relevant to bring it up then since the volunteer opportunity was through the Foundation. I've learned if you don't trust anyone, then nobody trusts you either. She was fine with hearing about it and I did learn why. I found out she wasn't perfect physically either, with a minor hearing impairment. But I think it had more to do with having been around the disorder before in her life. She shared how a close friend has epilepsy and it's a bigger deal in her friend's life than in mine. I was informed how her friend doesn't have a driver license and takes plenty of medication. I don't know what kinds of meds as I haven't asked about it. I do see her every so often. Thankfully she has a pleasant demeanor despite the disorder. It annoys me when I've seen some who use any excuse, including epilepsy, to have a sour attitude about life and dump on everybody. I was also informed how this friend has cerebral palsy, though I was unable to tell how she has either disorder. I know she hasn't had a seizure around me. This is how it should be, where it is hard to tell when one has a particular condition. It's easier to judge them by their own merits then. When there are advocacy groups and medical advancements to help many lead more normal lives, there is less of a need for excuses, and the 'victim mentality'.

I knew it was best to practice full disclosure on more than just my history of epilepsy. So I did speak of having syringomyella, the spinal cord injury. I said it hasn't had a big effect on my life yet, as I am still very mobile and independent. I do take Lyrica for it, and so far so good, more than four years since being diagnosed I am fine. Even though the chance of paralysis doesn't thrill me, it has taught me to value each day more than I did. My physician advised me to avoid high risk activities like horseback riding and skiing. My lady tells me having to avoid those activities is no big deal at all. I like knowing that she tells me she hasn't told her family and friends about all of it, when they don't need to know. I wouldn't want all of the questions about it, wondering if I was damaged goods. I still like thinking about what I can do instead of what I can't. I'm still doing comedy and I like the feeling of finding something I'm good at. I've seen how my jokes are better now since I'm in a relationship. There are some jokes I won't do and won't laugh at, like jokes about neurological disorders including epilepsy, as those jokes just aren't funny to me.

I have had my lady with me at some of the events sponsored by the Foundation. I attend when available but there have been some scheduling conflicts, same as any other year. I've learned plenty about myself, and value myself more due to dating somebody. It meant having to ask her what she likes about me to satisfy my curiosity. I know how only one gets out of something what they put into it and I know I've been trying harder with her when it's more worthwhile than the others. We have some important things in common, as we both majored in history in college. She doesn't have the same character flaws as some of the others, like a drinking problem or being mouthy. Attitude makes the difference, and I had to get over the obstacle of being 'found out' related to my history of epilepsy. Thankfully somebody is willing to accept me for who I am. The best is yet to come for me.

* * *

L.E. LaRue
Age 37, person with epilepsy

The inspiration for my written work is my life. Epilepsy did affect my life some hard to say how much. Thankfully it wasn't serious enough to prevent me from getting a driver's license. Finding the Foundation was helpful, as I became more accepting and less ashamed of the disorder. I don't share having the disorder with many, afraid of being judged too harshly because of it due to ignorance.

I was diagnosed with epilepsy at age 4 and was on Dilantin until age 10. Seizures are rare now, once a year or less often. I have a degree in history from the University of Iowa and I once received treatment for epilepsy at the university's hospital.

Life with Epilepsy

by Tamerra Levi

Life with epilepsy is good
Life with epilepsy is bad
Sometimes life with epilepsy is even sad
Sometimes you have to fight
But when you get it right
Your life will turn out alright.

Tamerra Levi
Age 15, person with epilepsy

I have simple partial seizures. I know I am special and that I learn differently than other kids my age. When I wrote this poem I kept thinking about how epilepsy affects kids' lives every day. How most kids go to school scared that they'll be walking down the hall and have a seizure in front of everyone. I also have to fight to overcome seizures but in the end, as my poem says, yours and my life will turn out alright so remember to keep fighting.

balancing act
november 8, 2011
by Jean Manrique

my balance is off

my doctor used to ask me
to walk the line
heel to toe
heel to toe

but no longer
he knows i can’t
put even one foot
in front of the other

the tree pose
is impossible
standing even on two feet
i may wobble
standing too quickly
i may swerve

but balance has become my leitmotif
i search for the yin and yang
the push and pull

i look for balance
between productivity
and rest
guilt
and absolvence
between a folding in
and an opening out

i seek to balance
subtractions
and additions
the glass half empty
with the glass half full
questions
with contentment
acceptance
with striving

but most of all
i pursue the balance
that will allow me
to make peace
between hope
and my reality

if you’re mad and you know it
october 20, 2011
by Jean Manrique

i’m walking
on this clear october day
i’m frustrated
upset
and i like it like that

i want to be frustrated
i’m tired of optimism
thinking how lucky i am
being thankful
hopeful
strong

i want to be frustrated
hell, forget frustrated
i’m mad

i can’t ride my slow bike
because i can’t find the key
even though i’ve looked five times
in all the same places
and i can’t ride my fast bike
because it’s in storage
and we live in an apartment
where there’s no room to keep a bike
that i probably won’t ride anyway
because most of the time i don’t feel good enough

i’m mad because all my all-weather bike riding clothes
including the warm waterproof gloves that i got on sale last year
at the end of the season
and don’t even have the tags taken off
are in a plastic box
in the furthest corner of my closet
under boxes of other things i don’t use very often anymore

i’m upset because
i can’t drive
my orange VW convertible bug
because it got squashed and totaled while parked on the street
in front of a coffee shop
and even though i couldn’t drive it anyway until my seizures stop for three months
which i doubt they ever will
i still liked riding in it
with the top down on a cold fall day
with the seats counteracting cold rushing air

i’m mad because we
live in an apartment now
and i miss my house and my neighborhood my neighbors my garden
and all the pretty things that made my garden a work of art
and an expression of me

and i’m mad because i’m not supposed to be mad

i want to be mad
to let it flow
to be wrapped in it
wallow awhile
without feeling guilty
or worrying about how others will feel if i let the mad out

i’m mad because since i can’t ride my bike because i can’t find my keys
i have to walk
and walking takes too long
because it gives me too long to think
because i don’t want to be guilty
because i’m not happy for the cool air
and intense colors
and my soft silk scarf that belonged to my stylish mother-in-law
and my lovely wool sweater from Ireland
that’s perfect as a jacket in october
because i want to be mad
and let it flow

but then i pass a group of teenagers
taking up the whole sidewalk
they’re laughing
talking
texting
one is riding a bike
one holds onto his skateboard
and i step aside to let them pass
and am glad to do so
because they are teenagers
enjoying a day off of school
and being themselves
and excited about life

then the one with that was texting
looks up
and our eyes meet
and he smiles at me
and i smile back
and against my will
i soften
and after we’ve passed
i begin to cry

scarecrow and i
august 10, 2011
by Jean Manrique

we're pals
mr. scarecrow and i

we don't mind the crows
as long as they don't linger
on our shoulders or heads

scarecrow and I
can both be a little slow
sometimes
in body and mind

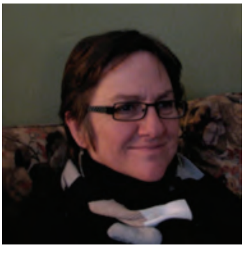
we both have a diploma
that doesn't do much good

we both want new brains
something better than straw

brand-new
spanking clean
greased up
ready-to-use
latest model
brains

do you know where we can find one?
because no matter how much i look
i just can't seem to find that Land of Oz

* * *



Jean Manrique
Age 55, person with epilepsy

I find that writing poetry when I am having a difficult time helps me to express my feelings in a creative way. I often begin composing the poem as I lie in bed trying to sleep and hope that I will remember what I've composed in the morning (sometimes I do, however sometimes I don't). In the past three years that I have experienced frequent complex partial seizures my life has continued to change. I have had to find a new way of living that allows me both to grieve my losses and rejoice in the things I have learned and gained.

Controlled But Not Cured

by Carol (Oxborough) Olson

My epilepsy
Will never be
A friend to me
It remains the enemy
It is always on my mind
Even when it’s being kind
Staying quiet and calm
Under a medicated balm
I always known it’s here
So I wait with constant fear
Wondering when it will reappear
Waiting with dread
For it to rear its ugly head
Sometimes I would have a dread
‘Aura’ or a sign of a seizure ahead
Like a weird taste, feeling, or migraine
That would give me an emotion of disdain
Hopefully I wouldn’t
Need to converse
Because I couldn’t
Find words; even worse
I would create a scene of woe
I really do not want that, NO!
Even if we can’t be close friends
We have in common some same ends
On which my life depends
My heart, my soul and my mind
All need to find
A place where life
Goes steadily on despite strife
Not getting stunted by fear
But stronger with each coming year

Epilepsy can be a challenge all right
But it’s one we can win if we fight!
Remember to seize the day
Don’t let this disease get in your way
Your brain renders this disease for you
But it holds intelligence too
This and faith in God will get you through

Carol (Oxborough) Olson
Age 59, person with epilepsy

At first things seemed dark indeed. No matter how many doctors I saw there just was no easy, quick fix. Meds were mixed in various ways with some success. After awhile, though, another seizure would happen. This turned my world upside down and it was back to square one. A lot of trial and error! When I got up the courage to tell co-workers I found plenty that were not receptive. Others were and could even tell me about friends and relatives like me. Now I am on Depakote. It is good for controlling seizures but it causes tremors. I mainly have psychomotor or tonic-clonic seizures with a combination of grand and petit mal. I am a divorced mother of three grown sons. I hold two degrees.

* * *

By the End of the Week

by Sarah Schmidt

We farm. He and I work together side by side. Not today.
This morning I had a seizure.
He is upset. He wishes I would take better care of myself.
He has our business to run.
He has to keep everything going.
He has to get his work done.
He has to get my work done.
He doesn't have time to dwell on "it".
He will check on me later.

He moves on. I am stuck.
He comes upstairs and opens our bedroom door. I hear his voice. My brain (the same brain that failed me this morning) puts a negative spin on everything he says.
What he says is, "Are you going to be OK to do calf chores tonight?"
What I hear is, "Are you going to get up and get something done today?"
What he says is, "I'm going to find something to eat. Then I have to get back outside."
What I hear is, "You've really screwed up my day."
What he says is, "I'll be out in the shop."
What I hear is, "If you need something, you know where you can find me."
He's right. Maybe I will feel better if I go outside for a while.
Maybe I should go to bed early tonight.
I'm right.   Maybe by the end of the week, the self-blame
the loneliness
the headaches will go away.
Maybe by the end of the week, I won't feel so worthless.
I won't feel so lost.
I won't feel so numb.
Maybe by the end of the week, I'll be ok.
I'll be back to normal.
I'll trust my brain.
Maybe by the end of the week, I'll feel like wearing makeup again.

Sarah Schmidt
Age 59, person with epilepsy

I needed to write, “By the End of the Week” as a seizure put me out of commission for awhile. It takes days for a seizure to finally and completely let go of me. As I continue to age, it takes more time and more effort to bounce back to normal. But, to put it in perspective, as I age, it takes more time and more effort to do quite a few things! The best thing that has come into my life is the generic form of Lamictal. Seizure frequency has been gratefully controlled. In addition, most of the negative side effects (of the brand name) are gone. The mood swings are no longer an issue. Once, my husband tenderly took me in his arms, looked deeply into my eyes, and said, “I like this Sarah.” His warmest compliment was said to one of our daughters. “Your mom is more of what she used to be.”

My St Croix River
Sept 9, 2011
by Karly Wahlin

It soothes and softens the hardness of life
lulling the trying images that run through our lives
            into a resting place

It offers peace in place of unrest
bringing joy to its passengers floating ever so safely on its surface
encouraging boldness where there was fear,
            noting a lifetime of caution

It's the perfect prescription!
no side effects noted, no complications observed
no bad habits formed
only moments that are perfect in its comforting presence

Thank you for being my new friend,
hearing my pleas for comfort and restored strength
understanding my need before I was aware of it

Thoughts In My Head
August 3, 2011

Talk is cheap they say
It comes so easily off the tongue
It rolls around mouths and exits into people's ears
forming thoughts in the listening heart

Talk is cheap for those who never think twice
about making sounds that form words
Words that form other people's opinions

But for those of us who have no words others can hear
their thoughts are formed by our appearance
by the lack of words,
never seeing beyond the visible
to hear the hearts who live in silence,
who live in bodies that betray their intellect

I say talk is cheap but thoughts are expensive
Thoughts formed without questions hurt many

Karly Wahlin
Age 26, person with epilepsy

I have lived for 26 years. Only my mother has heard me speak. I was nine months old and I said “meow” when we were reading a book together. It was the first and last word I ever spoke. I tried really hard to speak but it has not been possible for me because of Rett syndrome. After years of therapy and questions, we got that diagnosis. Many things changed. It was a burden to be a young girl with Rett syndrome because little was expected of me by everyone but my mom. She knew I was in here. She believed when others talked about her behind her back. I heard them. My story is one of great joy and happiness because, in spite of all the things that have been taken away from me in my life, I have had many great gifts. I hope when you meet someone who is unable to speak that you assume they are intelligent. It may change their life to have just one person believe.

The Life That Was

by Susan Welshinger

Back in the 50's, 60's, and 70's, I once knew a little girl. She lived in her own world and nobody wanted a part of. And today she is still on her own with occasional help to get by. But she still wonders. But in turn she is making it. She cannot be stopped and presses on. She is now an adult going on with life, doing what she's been taught to survive. Learning she cannot fix other people but only being what she has become, being more confident about herself with self-esteem, now exploring the mysteries of her mind and the loving God she has come to know. His peace, now a piece of her, in this evil world of hate, schemes and deceit. For she has found herself and years of her life, growing up in an era when no specialists were around. Well, that little girl was me. Now that I have grown up and matured with that occasional help, I have learned it is not about the past and what was, but is the present and what is, plus being positive about and looking for the good in life in this journey I am on. With God walking besides me, I lean on His help and His strength to pull me through...If God goes before me He will make a way in all I do, as He has done with others before me. The help I have had was needed and has kept me grounded when I felt in need of that extra support. It was been a fight but I am climbing my way back.

Susan Welshinger
Age 58, person with epilepsy

My inner self inspired this short story. After all these years and even with surgery I still struggle psychologically. I still do not feel a part of. I do not always feel like I belong.

One thing I learned a long time ago was, that people's speculation of any disability, especially epilepsy, can often be misinterpreted or improperly understood. In essence, a person with epilepsy can speak about the realities it can cause, but those who speculate on it are not aware of what epilepsy brings to one in their life and lifestyle.

Movements of Love

writings by family, friends and caregivers
of people with epilepsy

Epilepsy

by Beth Bacon

My youngest son
Has epilepsy
A word, a disease
That I was not familiar with
Nor do I know how to fight
It was so hard to explain
A two month old with rigid body
Shaking to and fro
The fear of a neurologist
No matter how nice
To watch a video EEG
Of a mother's moments
Nursing and caring for her child
Overnight in the hospital
That specialized in sick children
Scared to death
That this is where we belong
Watching my husband
Go back and forth to care and
support
Our other children and me
The tests they ran
Pictures of my baby's brain
Dyes to show his insides
Anesthesiologist to sedate him
Long hallways and long waits
Blood tests and IV's
Hoping the find something
To explain
And equally hoping
To find nothing to explain
Then home we go
A medication to try
Conversations of brain mapping
Temporal lobes
To explain this two month old
Until another day
Another drive
My son seemed gone
Not aware
Back we go
As we start to learn the lingo
Of epilepsy
Focal seizures
My child

Nighttime fall 2010

I have been waiting all day
To go night-night with you.
My son curls up in my arms
His words wrapping around my heart
Why did it take so long
For the night to come?

Had I known I would have pulled the curtains
He is asleep instantly
I lay there wide awake
Wishing I could have made his day better
I curl around him now
Content to feel his heart beat
Against my chest
Close my eyes and mind to the day
Hold onto this boy
I wish I knew what secrets he had
That made his voice quiver
When I asked him of his day

Permagrin Saturday

by Beth Bacon

Permagrin Saturday
Five years old
Highlight of his day
Outdoor pool opening day
Graduated entry
Sprayers and fountains
The big blue slide
To challenge fears
We wonder why
Every day he begs
For the outdoor pool
As he spins in water over his head
My arms outstretched
Just in case
His father watching
Two feet away
His brothers circling
At the pool He is our center
The axis of our world
The older brothers jump in
After waving to him to watch
I climb the stairs
Of that big blue slide
To watch him
Following his brother
Conquering his fear
Circle down
Twist and turn
To end in the pool
With his dad and brothers
Waiting at the landing
Permagrin
I do it myself
With all of us to watch
And wonder
How joyful that smile
One, two, three blastoff
The sun kisses his cheeks
As we lean into him
Permagrin
Day at the pool
Beaming at us all

Beth Bacon
Age 43, son has epilepsy

My son, Benjamin was diagnosed with epilepsy when he was two months old. He is now a wonderful five-year-old that is treated with Lamictal and Topamax. He has brought so much joy and laughter into our family; we are constantly inspired by him. Ben has focal and absence seizures normally lasting 30 seconds to 3 minutes in length. He has speech and learning disabilities as a result. For every challenge we have faced with our son through this process, we have also been blessed with a child that has a tremendous capacity for love, humor and joy in his life. It will always be our goals to live up to his potential, and help him overcome the stigmas and stereotypes that he is faced with and watch him succeed!

My Garrett

by Carrie Edberg

He, my son, stares into space.
I get right down by his face.

“Garrett hello”
“Garrett hello”

Seconds later he’ll look at me.
He doesn’t know what I see.

It happens here and it happens there.
People think he just doesn’t care.

Absence seizures is what it is.
Its 4 years of what doctors missed.

Medication is his new game.
Now my Garrett responds to his name.

“Garrett hello”
“Garrett hello”

“Yes Mommy.
I Love you so”

* * *

Carrie Edberg
Age 34, son has epilepsy

My son Garrett is 8years old. He has focal and generalized seizures due to myelin steath-the brain did not develop normally.

we dance

by Angela Halverson

a gentle breeze of acceptance blows around us
with more consistency as the seasons pass
it floats in the air lightly, invisibly, purely
the sun shines warm on our bodies and our souls
a sweet peace flows through our veins
nothing has changed really
the seizures are still there
some days just under the surface
some days rearing their gnarled, ugly faces
but time and love and laughter heal broken hearts and weary minds
we live
we work
we pray
we deal
we dance
with whatever comes our way
we are old pros
we've earned our stars and stripes
we've earned our purple hearts
no seizure will get in the way of our determination
to live this life that God has given us
we are tougher than seizures
we are smarter than seizures
we will not worry over that which we cannot control
but we won't give up the fight

The PCA

by Angela Halverson

In the beginning, they all come into our home
with happy voices and professions of kindness and devotion
to land the job
They come each day and earn their pay
the work is not always easy
They bring him into their lives
into their families
calling him their own
he extends the same, unconditionally

They are paid friends, of course
but friends none-the-less, right?
(time is beginning to show otherwise)
Above and beyond wages,
they receive his gifts of love and trust
the life lessons he teaches
without knowing, without trying
They become better people for having known him

But then, inevitably, they go
a better job
better pay
blah,blah,blah….the excuses flow
And he is left wondering
where did they go?
what did I do?

They are replaced with newer models
sometimes better, sometimes worse
it really doesn't matter.
In the end, each one will go
leaving behind a heartbroken boy
with a mom desperately trying to pick up the pieces
fill in the holes
and run the next ad

* * *

Angela Halverson
Age 39, son has epilepsy

My son Evan, age 12 and my daughter Ellie, age 5, are my inspirations. I do not know who I would be without my children. I cannot remember who I was before I was a mom. Evan has Lennox-Gastaut and now that he is a Tween, his seizures are a little more active. We just take it all one day at a time. My poem, "we dance" says it all. My second poem, The PCA, channels my frustration with the turnover in personal care attendants. The worst part is Evan never understands why or where they go.

STORY TELLER

by Jerry Hartlaub

Hearing travel and books, some TV and jokes.
Enthused by his looks and sounds of hope.
Options to cover, ground to explore.
Pausing for others, connections galore.

Amazing recall of months and years past.
Details installed, few mortals could cast.
Sometimes he's subtle, more often direct.
Avoiding trouble, not what you'd expect.

Enjoying the center, connecting with pride.
Often the better, taking a side.
He'll lend an ear but don't take a break.
Quick to proceed, if only for your sake.

Sometimes convincing, often in jest.
Soon he's listening, put to the test.
Rarely a pause, why take a rest.
Maybe applause, don't care who's best.

Encounter a treat, enjoy the occasion.
Rush to your seat, a ready ovation.
May be a fine artist, could be a seller,
I know he's the smartest, the best Story Teller

Jerry Hartlaub
Age 71, son has epilepsy

This poem was inspired by my adult son. He is an accomplished, gentle man, husband and father.
As a child he underwent a craniotomy to remove a tumor. The first prognosis was very bad but after many years the outcome was been very good. He grew to be a normal adult, earning a PhD, is happily married and teaches at the college level. While in his college program he experienced his first seizure. Since that time (about 25 years ago) he has pressed forward with his life while using meds for good seizure control. And he has courageously overcome transient major drug side effects while living his life very effectively. I have been an anxious observer, listener and advisor. He has carried the seizure risk burden with dignity, and I am impressed and humbled. When I considered entering this writing contest, I was again mindful of how proud I am of my son. This contest has provided an avenue for me to express my feelings.

Shhh! We don’t talk about “THAT”…

12/2/2010

by Debora Joyce

Our family has had a secret for over 100 years **Epilepsy.**
My great grandmother was born in the late 1800’s in Norway, married and immigrated to this country at the turn of the century. What no one talked about was the secret she carried with her, that she had epilepsy. Her life went on, and she had a family, she laughed, she cried, she died and no one ever talked about her… epilepsy.’

My grandfather was born at the beginning of this century and he inherited my great grandmother’s secret, epilepsy. Again, **“THAT”** was never talked about and he too went on to marry have a family, a business, he laughed, he cried, he died, and again no ever talked about his… epilepsy.

I met the man who was to be my soul mate and one day he asked to have a serious conversation. My blood ran cold because as girls well know, it could mean only one of two things when you hear those words. He went on to explain to me that he had epilepsy and had been afraid to tell me because he had been raised not to talk about **“THAT”.** After a sigh of relief, I told him I had heard that I had epilepsy in my family so don’t worry! We married; we went on with life we laughed, we cried and again no ever talked about his… epilepsy then we had a surprise!

Spencer our son was born and again we gave no thought to epilepsy. So life went on. We laughed, we cried, and again no ever talked about … epilepsy and then we had another Surprise!

Allison our daughter was born and again we gave no thought to epilepsy. So life went on. We laughed we cried and again no ever talked about … epilepsy, then we had another Surprise!

But this time it was epilepsy that gave us the surprise and it was time to start talking about **“THAT”!**

Spencer was diagnosed first in the 5th grade and as his parent I did not want to keep epilepsy in the dark and a secret. With the help of many we educated him, ourselves and the school so he could feel comfortable with talking about his epilepsy. Life went on. We laughed, we cried and we talked but… we got surprise number 2.

Allison was diagnosed in the 3rd grade with epilepsy. Since we had open communication about Epilepsy she thought she was joining a special club and was thrilled! It’s taken over 100 years, but now we live, laugh, and cry but we talk openly about Epilepsy.

Dedicated: To all my family Past and Present living with epilepsy
I Love You ALL!!!!!

Debora Joyce
Son, daughter, husband have epilepsy

I have been married to my husband David for 25 years. We have 2 beautiful children, Spencer, age 15 and Allison, age 10. Since they have entered our lives they have brought us on an adventure that we could have never imagined and would have never missed. I work for the Alzheimer's Association, which is another great learning experience.

My GPS

by Chris Poshek

Some people say life is about the choices we make. The choices can define us. Whether we make good or bad choices, the results will be different. But the choice we did not make will always make us wonder. Did I or have I made the right choice? If life is a highway, then I could say my highway is under construction. When people look at their life choices, some view it as an open highway. Others look at it as a country road. The simple fact is we will all come to a fork in the road. When faced with a decision on my career choices, I viewed the possibilities and decided to make a difference.

As I begin my journey towards an exciting future, I have one road that is filled with bumps and bruises. It involves a bumpy road that included two tonic clonic seizures. It also was paved with dealing with my daughter Hannah's epilepsy as well. This road is behind me in the rear view mirror. The other path is familiar. My work experience has allowed me to learn a craft. Tomorrow I could choose the road to the food service industry and excel. But would I be making a difference? Would I truly be happy? This career choice is the easy route. The question I have to ask myself is this, "Do I want the easy road that is paved? Or do I want the bumpy road that is full of dips and curves?" I made my decision. I knew the road less traveled was the path I wanted to take.

I used to think I was born to be the best dad possible to my little girl, Hannah. It wasn't until recently that it became apparent what I was meant to do. And that was to make a difference in a child's life. With the combination of education and leadership, I know that early education is my career path. The next road will take me to Bemidji State to get my bachelor's degree in early childhood education. And part of that road will finish with an emphasis in special education. By choosing this path, I will be able to make a difference in children's lives. My highway is a long road trip. But I have my mixed CD in the car and I'm eager to start the trip.

As one takes a look at this journey we call life, there are many twists and turns. The passions, education and family we have will be the GPS of our journey. Not every stop goes as planned. And there might be a breakdown or two along the way. I have realized that the road trip in life is half the fun of the journey. By not having a few bumps along the way, it would make for a pretty dull trip we call life. But as I look back on the paths I have chosen in my life, I know there was no right or wrong answer. I would not trade the sadness and pain I have gone through to get to this point. All the roads I have chosen have led me to this very crossroad. I am positive that I have the tools I need to begin this adventure. Some people would choose the super speedway but I'm choosing the back roads filled with unexpected adventures. So I'm popping in that CD, cranking up the music and am ready for the greatest trip of my life.

Chris Poshek
Age 40, person with epilepsy, daughter has epilepsy

This piece was inspired by my daughter Hannah and my family. They have allowed me to share my story with those affected by epilepsy and make a difference in people's lives. I am prone to tonic clonic seizures but haven't had one in over seven years. My daughter's seizures are a constant battle on a daily basis.

Marky Mark

by Matt Schallinger

I'm riding in the front seat of an emotional roller coaster. Climbing mountains of fright, on through dark tunnels of confusion and down open chutes of optimism, makes my head very cloudy. I think I can see the end of this crazy ride looming in the distance. Making our approach I suspect a squealing halt, yet surprisingly it was a smooth landing. A familiar excitement began to brew in my young, eager body. I am running free, away from that unstable excursion and absorbing every warming emotion at my fingertips. Looking back at it all, this would be my best guess as to what my brother was experiencing the day that I took him to the Mall of America.

My brother Mark doesn't get out much, generally residing in and around the confines of our neighborhood cul-de-sac. His main hobby is becoming endlessly absorbed in video games and some intense knee hockey on the side. He also dominates in basketball, how I do not know, but he always seems to find a way to beat me in the classic game of PIG. Like his basketball skills, I also do not know much about his epilepsy. Aware that it entails a multitude of seizures, electrical attacks on the brain but I'm not sure how to actually live with it. I feel like I should though, after all I have spent the last 17 years of my life with him and hardly ever did I examine life from his eyes. I can only now imagine what it must be like to experience a hurricane of electrically firing neurons ferociously attacking your mind, inhibiting the ability to control yourself, all the while feeling completely helpless. Not to mention the numerous trips to the doctor and side effects like social impairment and physical instability. Nonetheless, my brother is a trooper, a professional you might say, in his department. He does not lead a life fearing the next big storm but rather one of caution. A necessary commitment, this caution leads him to a life of limitations, yet it should not hold him back from experiencing the world.

As we stepped into the car we casually put on our game faces. For us, this is no ordinary shopping trip; the rules of epilepsy throw constraints on what may seem like a normal experience. There is a need for constantly applied caution. Unexpected events can occur out of nowhere placing an interesting twist on the current situation that tests your ability for adaptation. It's not every day that my brother and I set out into places like these. Leaving the warmth and security of home to venture out beyond the limits of comfort can be unnerving, yet that is the essence of a high stakes competition. Nonetheless, we buckle up and set off into the afternoon sun.

Upon our grand entrance through the doors we were welcomed with a rush of commotion. Everywhere people were shopping, eating and becoming swallowed up in the vastness of the mall itself. My brother was also welcomed with intense vertigo, something I severely miscalculated. Like an Atlas, the whole weight of the world had come down on his unstable shoulders. He grabbed me for dear life, giving the impression he was about to fall off a steep, rocky cliff into a world with no support. I never experienced anything like it and honestly I was quite scared. Nervous and awestruck, I somehow transported us to a bench where we could reassess our current dilemma. Now I know why he was initially so hesitant to come to this crazy place. I instinctively found myself asking if he wanted to go home and he gave me a stern response entailing the courage needed to go through with this. With this, we put ourselves back together like building blocks and set out to explore. To make any progress was as if we were wading through deep, thick mud that required his arm latched around my hip and the other resting on my shoulder. Slowly we were able to move, along with my arms to provide the supporting upright posture. Moving in a way that was so obscure lead me to the most emotionally uncomfortable experience I have ever been in. All I was able to notice were the other shoppers relentlessly staring at our situation and I was ever curious what they might think of all this. I felt vulnerable to the generalizations that would be made about my brother and yet there is nothing that could prevent it. I had to do away with these concerns in order to give my brother the appearance that I was comfortable in my assistance to him.

Confidence soon set in my stride, the burden was lifted and I concentrated on us now. As if finally parachuting back to reality, I found that our companionship made things go much easier. Still placing one foot in front of the other we were like a train that was slowly gaining its momentum and the bite of his grip began to loosen its hold on my body. With his strength filling up in his legs and confidence pouring into his chest he was soon walking independently. There were times when he needed to latch onto me, like sudden and subtle seizures, yet he continued to fight with each step as his coach encouraged from the background. There was a desire in my brother's deep blue eyes that longed for more adventure, meaning we would need to ascend the escalators to a brand new level. He was bothered knowing that the vertigo would take hold again due to the change in elevation but he put that aside and bravely accepted it. Rising above the heads of shoppers was like taking punch after punch, and the crowd was left anticipating when he would be knocked down. With a couple steps taken off the escalator Mark fell into my supporting embrace, yet this time we were better prepared and calmly we set out. As a world class boxer in his final round, my brother battled his way back to a position where he could carry himself and his confidence.

It was on the third and topmost floor that I became bewildered. Mazes of tables and ledges that were peering over steep drop-offs created an environment that was ideal for the crumbling effects of his vertigo. The openness of the food court made it seem like there was nothing to grab on to, alone and completely separated from the tunnels that contained all the shops. It was here that Mark decided to leave me and run ahead somewhere. I could only stand back for a second and watch his every move, absorbing everything he was. How could someone like my brother accomplish such a feat? How was he able to just leave something he was so dependent on and run off into the distance? Apparently it was the great golden arches of McDonald's that had this magical power. As I caught up to him in line I was greeted by a smile that I would never forget, a smile of

true achievement. He appeared so unaware and ignorant of the struggle we just went through for the past two hours. It was as if the limits of the vertigo that were placed on him completely shattered to pieces, freeing him from whatever was holding him back. The weight of the world was now lifted and we could finally enjoy our trip at the nation's most vibrant mall.
All he got out of that trip was a simple shirt from one of the shops we visited but that was a memento worth fighting for.

That night everything appeared back to normal. Mark was playing his video games and I was out somewhere with friends. It wasn't until later that I realized I was taught a lesson, a lesson on limitations and acceptance. Everyday my brother is held back by his epilepsy and cannot do half the things I am able to do, yet I hardly give him the opportunity to experience what I take for granted. This is because I am afraid that he will hold me back, impatient for him to take the time and catch up to me. Now I realize how important it is for me to slow myself down when I am with him. I do not want to miss the train but I also cannot live with the fact that I left my own brother on the platform and it wasn't until I was left alone on this deserted island with him that I could see where we were. I accepted the limitations of his vertigo. Seeing the waves of people passing us by when stranded on the bench led me to conclude that there would be other trains to catch up to them and we were in no rush to make that happen.

Limitations are like labels, a customized name tag depicting what is holding us back. Everyone is aware of the tag they carry and the difference between people is how they wear it. Some labels are easy to conceal, hidden behind a nice fur coat or superb athletic ability. Others are not so easy to live with, labels that you cannot become separated from through using material objects or a jersey. My brother Mark wears a label everyday of his life; he cannot hide it from the rest of society or himself. I cannot hide his disability from me or my friends and this is something that I finally accepted. When I took Mark to the mall I learned that labels do not define us humans. The shoppers saw my brother's label as crippled and they were right but they were wrong in thinking that he would always have to wear it. With my help he was able to rid himself of that brand and be seen as independent. Having any sort of disability is unfortunate, yet by no means should it constrain our dreams or life. It is those with a weakness who are in need for someone to understand them, someone to connect with and to help alleviate the burden of a label.

Matt Schallinger
Age 19, brother has epilepsy

The inspiration behind this piece of work lies within my brother Mark. I have witnessed firsthand how epilepsy has affected his life and the setbacks they induce. It is simply not fair to him and anyone else out there who has a disability, yet that's just the way it is. I better understand now how seizures have affected his life and thus mine. My brother's epilepsy puts into perspective how our lives differ. Going to the mall is a leisurely stroll for most people, whereas for people with a disability it could be comparable to climbing Mt. Everest. Despite these differences we are all still human; we go through the same emotions and thoughts just like everyone else. Many people in today's society forget this truth and conjure up some "label" to associate with something they are unfamiliar with. We are all guilty of doing this and we do it because it makes our lives easier. However, I continue to challenge myself to see around these differences and come back to the basis that we are all human, disability or no disability. I feel that if people can challenge themselves to look into a special needs person they will ultimately find some reflection of themselves beaming out back at them, shedding light onto the fact that we are in this together.

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