Epilogues 2010

a collection of written works displaying the talents
of people affected by seizures

EPILEPSY
FOUNDATION®
MINNESOTA

Our Mission

The Epilepsy Foundation of Minnesota leads the fight to stop seizures, find a cure and overcome the challenges created by epilepsy.

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Introduction

Dear Epilogues Collection Reader,

We are delighted to publish the 4th edition of Epilogues in 2010! This book of written works, including poetry and prose, was compiled by the Epilepsy Foundation of Minnesota (EFM). These written works were created by authors living with epilepsy or having a close relationship to a person with this disorder.

The Epilogues Collection is intended to provide a creative outlet for personal expression and to raise the public awareness of the disorder of epilepsy. To give greater understanding and meaning to the works, background information provided by each author is included.

The Epilogues Collection Committee of EFM received the works in this book during September and October of 2010. The Committee grouped all written works into three classes - Judges' Choice, Superior, and Meritorious – in a poetry category and a prose category. Author recognition included a meaningful Enduring Item, Certificate, a Letter of Appreciation, a copy of this book and possible public readings or further publication of works on behalf of EFM.

The Committee recognizes our volunteer copyeditor-one of our authors-Jean Manrique who with swiftness and thoughtfulness ensured that all works were correct both in grammar and in meaning. We organized the writings, again, this year, into two sections in the book: *Sustaining Ourselves - writings by people with epilepsy*; and *Movements of Love - writings by family, friends and caregivers of people with epilepsy*. Poems and prose pieces are logically placed in alphabetical order within each category.

It is our honor to congratulate each author for creating their written work and then submitting it to EFM. Some of the authors you may recognize from previous years. Others are new to Epilogues and new to EFM. As always, we wish all involved in the project that is Epilogues well and thank you for your contribution-your words not only raise awareness about epilepsy but also connect our community together.

Epilogues Collection Committee

Sustaining Ourselves
writings by people with epilepsy

Molly Cooney
Age 36, 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. "Holding" is an excerpt from the memoir.

Holding

So this is the one that gets me. Or this. Or maybe the next.

Waking up from a seizure, fogged and sore, it takes a minute to jostle from my head that it didn't, in fact, get me. Eyes blink, the small shift of my fingers and release of my shoulders as I see someone's eyes, hear breathing and feel a hand on my arm that helps me gently unfold the reality that I'm okay. I'm not alone in that numb pause of post-seizure relief. Every epileptic has those escape stories, and somehow, despite my own constant fear, hearing about others who slipped, however narrowly, passed *the one that gets me*, helps me stand up and shimmy off my own seizure. The palpable fear melts into visceral relief that is, for me, not without guilt, and I feel the sharp familiar realization that my epilepsy wears a relative mildness that disguises itself, sometimes even from myself.

Since my first seizure I have gathered stories from friends and friends of friends, coworkers, distant relatives, the mail lady, the pizza guy and hundreds of books and essays. I even received a few letters from seeming strangers who got my name from so-and-so. I listened hungrily, read voraciously, craving stories worse than mine. I didn't, and still don't fully understand this developing fascination that captivates me, but I continue to research with some sort of guilty pleasure that tethers me to my mother's voice:

"You've only had one *real* seizure…thank God you're alive…think of the kids who can't walk or don't have food today." And I do.

A neighbor told me how her three-week-old was crying in that normal baby way, and then began jerking her arms and held her breath until she turned blue. "She was just really worked up, hungry probably, or frustrated about something," the ER doc said. The neighbor sighed when she told me, "They were nice enough about trying to reassure me, but I knew it wasn't a tantrum." The baby did it again the next day. And the next. The bouts grew faster and more frequent until the doctor witnessed an episode and knew it wasn't colic or anything so simple. *Seizures.* If they didn't kill her baby, they would destroy her tiny brain and any chance of fully functioning in the world.

A friend's uncle was a lawyer, Harvard grad, engaged, who began to stutter one day in the courtroom. *Nerves*, he thought. For the next week he stumbled over words, fought through tangled thoughts but couldn't disguise his vacant eyes. Over the next couple of weeks he started losing easy cases then losing clients then losing his job. He lost his fiancé. His mom drove from three states away to pick up her 33-year-old son. His epilepsy had stormed in and within a month he was having fifty seizures a day. That's two every hour.

The seizures were small partial seizures that hit like scatter lightening, but each flash damaged his memory and each seizure carved a clearer path for the next one to follow. The doctors tossed medication at him—what else could they do? Finding the right combination is a game of luck, of tossing pills like dice on a table. It's a game of trial and error, setting different combinations of pills next to each other like lottery numbers. No medication, no combination of medications, no quantity of medication could stop his seizing. Over the next year he lost his ability to read or communicate full thoughts or even know what he wanted. He wandered from room to room; picking things up and setting them back down.

I hear these stories and my mom echoes in me, "You've only had one *real* seizure…thank God you're alive…think of the kids who can't walk or don't have food today."

"One *real* seizure."

Krista and Tim married, knowing she had epilepsy that was under control. About a year later she felt sick one night. "Tired really. My head hurts and my body aches," she said and went to bed early. The 10 o'clock news and some dishes later Tim crawled in next to her. "Krista, sweetie?" No shifting, no breathing. "Answer me, Krista. Dammit, answer me." Sudden death due to epilepsy.

I went to an epilepsy support meeting and heard stories about twin toddlers with intractable seizures, a teenager wearing a skateboard helmet at school, a dad whose ex-wife denied their child's epilepsy and refused medication, a wheelchaired woman who seized and crashed her car in a ditch, an aunt who dropped her newborn nephew. *It could be me*, I thought. But it wasn't. I didn't want to tell the group about my seizures because I was strangely embarrassed that they were, at this point, so subtle and essentially harmless. I felt like a fake, like I didn't really have epilepsy.

This costume of health has been hanging from my tough shoulders for ten years, sometimes tightly, sometimes loosely with breakthrough seizures sneaking through the seams. But as I tighten my bike helmet and click the pedals for my snowy, hour-long work commute or wake up stiff, my hand jerking to neck while I check to see if I taste blood, I can't deny the reality of it. *Me, really? Epilepsy?* I wake up to this mantra nearly every morning. *Really?* Every night.

When I slip into the hammering MRI tunnel, head in a cage, IV deep in my arm. Or slog into the clinic, intentionally sleep deprived to exaggerate my brainwave responses to stimuli, and lie on the bed with electrodes snaking from my head so the doctors can flash strobes and force hyperventilation, trying to induce seizures. The EEG machine looks older than my mother as the thin metal ink tips quiver across the scrolling paper strip, dropping and rising slightly, shaking wave patterns that are my brain activity. Or when I check into the hospital for another brain study, sleeping with raised bars and constant monitoring. When they told me I'd never get off medication. Those are the moments I know I'm not as minor a case as I pretend to be.

"Thank god you're alive." There she is again.

On and off breakthrough seizures mean I lose my license, sometimes for a year at a time, and I can't shower alone in the house. When the seizures continue to bust through the curtain of drugs, I have to switch medication. Many people with epilepsy struggle to find a medication that fully blocks their seizures. There's a 90% chance the first drug will block the seizures. If the first drug doesn't work, there is a 30% chance the second will work. If that one fails too, there is a 10% chance the third will work. It took me three.

If medications prove ineffective then it's invasive, like vagus nerve stimulators and brain surgery. Sometimes as extreme as severing the connections between the two hemispheres of the brain or removing chucks of brain matter. If all goes well the brain compensates, but never fully. How could it? There must be unknown reasons that the hemispheres communicate with one another in healthy brains. And even after slicing your head open, sometimes the seizures stop…sometimes they don't. Real life roulette.

White coated round pills with a red stamped T, blue powdery shields with letters carved in, tiny white pellets or green capsules. I'm sure there are pink and yellow too. The options seem endless, but for someone who can't find a pill that stops their seizures, the limited array feels strangling.

Some people find a medication that initially controls the attacks but loses its effectiveness after a month or a year, maybe two. I understand that experience because it's happened twice to me.

"Every couple of days, usually. One seizure a week for sure."

"It's time to switch," my neurologist said.

"I'm going backpacking in Peru next month."

He raised his eyebrow. "You're non-stop."

I smiled.

"The risks are real," he said. "High, but you know that."

I nodded.

"It's serious." He smiled. "But so is Machu Picchu. We'll switch meds after the Andes. Have fun."

Here comes my mom: "You could die. It's not worth it."

I know, I say to her phantom voice.

"It's not worth it."

But it's my life, I mutter, shaking her out of my mind.

To switch medications: Tegretol to Dilantin to Lamical, I overlapped drugs for months, waiting for the new drug to reach therapeutic levels before tapering off the old medication painfully slowly to avoid shocking my system into a grand mal. The double medication makes me feel light and confused, like I'm drunk.

But for some people with epilepsy this medication failure becomes an unstoppable pattern as they rip through drugs. Multiple meds usually block the seizures but drug the person into oblivion with exaggerated dizziness, confusion, forgetfulness and exhaustion. With a permanent regimen of several medications the side effects magnify exponentially so that it's hard to tell if it's the disorder or the supposed solution to the disorder that is causing the problems. It's hard not to wonder what does more damage over time—the seizures or the toxic medication levels. It's hard not to wonder if it's worth it.

So far, a solo drug works for me. I tried three different medications, but I made the 10% and am essentially controlled. Currently my neurology visits happen only twice a year. In telling my story, my terrifying and dramatic moments, I'm not trying to make my situation seem worse or compare myself to the devastating cases. But what others live doesn't change the fact that I have seizures or that over time my medications lose effectiveness and that the doctors don't know if that pattern will continue. The brain scars hint yes. There's still talk of continued decline. They talk about brain surgery. I'm not exaggerating. I live it.

"Thank god you're alive."

I do, mom. But I need space to grieve too. To be pissed if I need to.

Tobi has several seizures every day, big ones, episodes that last several minutes, sometimes half an hour. She feels an intense heat and overwhelming panic flashes her face. She stands up, rigid and strong as hell and bounces all over the room as if on a pogo stick. Tobi leaps onto the table and does her jerky dance, snorting and pissing her pants. Her classmates stare. Because of the noise, the doctors know she can breathe somewhat during the seizures, but when she reenters the world she can't remember anything—not the seizure or anything from the hours preceding it. Each time: brain damage. "It's Tuesday. You're in math class," her friend whispers to Tobi as if no one else noticed the scene and she could hide it in a quiet voice. If Tobi still didn't register, couldn't focus her eyes, the friend would lead her to the couch still whispering, "Tobi. Your name is Tobi. I'm Melissa. We're fourteen. We live in Denver."

Tobi would never drive, never live on her own and never escape the fear of performing this routine in public. She tried to work at a movie theater when she turned eighteen, but she couldn't discriminate between five and ten dollar bills. In one night she mistakenly gave away two hundred dollars and was fired on the spot.

The more stories I hear, the stranger seizure disorders appear. Essentially there are as many kinds of seizures as there are people because a brain misfire manifests itself distinctly in each person and often differently even in that same person. No two expressions are the same and no two responses are the same. The brain is one big jiggle of mystery, and trying to change its behaviors is nearly impossible.

A grand mal is the most severe, an entire brain malfunction, and the kind of seizure that landed me in the ER. It's the textbook image of a person flopping and jerking on the ground—the image that mistakenly led us to believe we have to restrain seizing victims, put something in their mouth so they don't bite their tongues off. Put your hand in a seizing mouth and its teeth will sink in. Pin a flailing leg and you'll get tossed against the wall. Just clear the space around the person so they don't hit anything, cushion their head and gently reassure them that it will pass.

Partial seizures are moments of disorientation or twitching that briefly disconnect an epileptic from reality. If a person disconnects from the world, it's a complex partial seizure. If they stay cognizant then it's a simple partial seizure. Momentary arm and spasms or uncontrollable head jerks. Continuous blinking or verbal tics. Lapse in short term memory or pause in conversation, often mid-sentence. Many, like me, stare straight-ahead, blank and unresponsive.

No one knows exactly how many people with epilepsy experience auras—subtle warnings of an imminent seizure. Usually an aura precedes the seizure by only a few seconds and may or may not give the person time to lie down, pop a pill or call for help. Auras manifest differently in each person: some feel suddenly tense or anxious, paranoid even, some hear music or tinkling sounds like wind chimes, some have a strange taste, often metallic, some smell a distinct odor like skunk spray and some experience a change in body temperature. My neighbor smells smoke before he hits the ground, a friend tastes bitter chocolate and knows the memory is coming, a coworker hears a train whistle and stops the car before her head slumps, bobs back up and slumps again, a friend's daughter feels dizzy and pops a pill to thwart the seizure. Countless ways with the common denominator that for most people with epilepsy an aura means, *prepare to hit the ground*.

Sometimes these auras are seizures themselves, and sometimes they crack into a grand mal. We just never know. I learned quickly to sense when I'm most at risk. To try to anticipate that stray electrical impulse tingling through my nerves, splashing like scatter-lightening, by noticing even the tiniest jitter in my stomach. Then that rising heat, the hollow, and I'd lie down. *Thunk.*

There is a tiny tunnel between the heat and the memory, just a split second entry when the fear burrows through my marrow. Although my medicine usually suspends me in that aura space, holds me perpetually in the intimations of heat, even though I often don't even reach the memory, fear still scrapes deep. Scours and scrapes me raw. It's my own body, my brain, attacking myself and there isn't anything I can do about it.

Because it's mostly a mystery when we'll drop and when we'll wake again, *if* we wake again, many of us with seizures exist in a swill of anxiety. *So this is the one that gets me.* Some people manage the fear better, some deny it, but it pervades every movement and permeates every moment. In reaction to this erratic potential, many people with epilepsy feel saved by pattern. If I do everything the same, everyday, without deviation, it may reduce the risk of seizures.

That was how my friend's brother Jesse deals with it. He wakes at the same time every day, takes his meds, then he eats breakfast and showers, just like anyone. His shower floor and walls are padded with vinyl pillows. He dresses and clips his helmet then sits down to comics and novels, depending on the intensity of his headache. Jesse won't leave the house unless he has a doctor's appointment or maybe to buy groceries. He's afraid to go to a café or a movie, *what if the sunlight flashes through the trees on the drive and triggers a seizure*, or *what if the pattern on the floor induces vertigo*, or *what if unexpectedly meeting a friend flashes into a déjà vu?* To him the risk isn't worth it. He sits home in his parent's house, helmet tight around his ears, passing his twenties reading sci-fi in the dim living room light. Pattern preserves his sanity.

"Think of the kids."

I read about a seven-year-old girl named Maggie who seized whenever she exercised hard and her heart rate increased too dramatically. Something about circulation and compensation. When the doctor hooked EEG electrodes to Maggie's head and monitored her brain activity while she slept, stared at flashing lights and experienced sudden noises, she saw no effect in Maggie's wave patterns. But the doctor witnessed her brain waves spike dramatically with increased respiration and heart rate, and, *bam*, Maggie hit the ground flopping. She could have stopped running, quit soccer, and avoided softball at the park with her friends. Instead Maggie spent her childhood trying to outsmart her own brain. She speed-walked the same distance every day, increasing the pace gradually so her heart rate rose only slightly.

Maggie began jogging in junior high, afraid at first, but more confident each time. Finally, having trained her body to handle the stress of an elevated heart and breathing rate, Maggie ran long distances. The doctors don't understand whether the seizures were actually trained out of her or if she just outgrew them. But Maggie conquered her fear through routine. When the risks remained the same, the pattern gave her courage and literally kept her moving. In high school she broke a track record. Mid-college she ran a marathon.

As I hear the stories, I try not to judge anyone's responses to their disorder or their loved one's disorder. I tell myself again and again, *there is no judgment, only witness*. The stories are simply for me to hear and pass along as various embodiments of the devastating disorder. The personal choices speak for themselves as do the human responses in the effort to survive.

I chose Machu Pichu, rock climbing and arctic paddling. It's not brave. It's not impressive. It's just living. Those choices don't make me special or exceptional. Depending on who you ask (my mom, for example) they may even make me ridiculous and unreasonable. But it's my choice, one of the many difficult options given to people with epilepsy. No matter how much control epilepsy steals from me, I control my response—we each do. Writing books, having babies, running marathons, floating rivers, meds or not. It's my choice, not yours. It's mine, not theirs. It's mine—and ours.

I was the program director of a youth epilepsy camp years after my diagnosis. For the eight –to-fifteen-year-old campers it was usually the first time away from home, horseback riding, water balloon fights, campfire songs and s'mores, sleeping in a tent. The way the campers shift the tag game slightly when a friend falls in a seizure, playing until the kid recovers and joins again. The way they step over their friend having a grand mal in the lunch line to get their fries and fruit. No one panics; no one stares. It's just the way it is. Camp is the one place the kids feel fully and completely normal.

Fourteen-year-old Karl is the camp hottie with his Sketchers and faux-hawk, with his tendency to drool. Twelve-year-old Samantha is the ringleader, gathering people for tag and ruling the dance floor even with her regular drops, the way her misshapen glasses bridge her nose from so many face falls. Eight-year-old Daniela repels down the climbing wall and walks away hand-in-hand with Hannah. The man from the climbing company says kindly, "Hey, you left your helmet on." Daniela keeps walking, unaware that he was talking to her, because the pink plastic helmet with ear loops and a chinstrap is her daily hat, pulled on in the morning like her socks and shirt. None of us even notice. The man's comments stab back the reality of how Daniela walks through the rest of her life outside this week at camp.

But ultimately it isn't about the ways in which other people with seizures struggle and I don't, how I'm lucky and they aren't, how they deal and I ignore. It isn't about how we are different, but about how we are the same. Similar, anyway. Regardless of age or triggers or symptoms and side effects, regardless of the level of devastation we live, we make our own small community. It's more complicated than dealing with scary stories and then turning to my own reality. It's simply about feeling like I'm not alone; like there are others who sleep and wake with the same fears, reality and wishes. After every conversation I feel a full warmth spread over my body, a good kind of warmth. Somehow that community, however close or distant, in giving itself words and faces, saves me every day.

Francine Coyan
Age 57, person with epilepsy

Epilepsy has been a battle that has affected employment, transportation, and lifestyle. My first seizure happened when I was 28 years old. Apparently, a birth defect did not make its appearance until growing into adulthood. “POWER” is about the nativity of man and his misuse of power whether aware of it or not. Man and his desires cannot be looked at in the same light as God's and must instead seek truth. This condition can be a frustrating, tearful journey and much of those tears caused by the fearfulness and misunderstanding of others. The most terrifying is loss of memory from long term use of drugs to combat seizures. When a friend recalls an event and you have no recollection, it becomes more apparent just how much you've lost to epilepsy.

Power

The natures of God and Man
Are not that dissimilar
Both seek to create
Both wish to see their creations grow and flourish
It is only with the advent of Power
That the similarity ends
For man, Power is the corrupter
Both God and Man have desires,
Yet man’s desires are often sought with no thought
To the effect or aftermath of obtaining the prize.
Many bring destruction and hardship on the other
In seeking their desires,
This is what we must change to become truly God-like
On what advancement we should aim
Before we may obtain
Enlightenment, Knowledge, and Truth.

Epilepsy

Life is a nightmare

When each day is as uncertain
As the next
When hope is that a day goes by
Without an incident
One less day of upheaval
Strange looks and uneasiness
Labeled as Fits, treated as hysteria, psychosis
Epilepsy meant mental defect
Today it is still a shrouded in mystery
Special? No
Different? Yes
Tell me then which is best,
When no one understands
What it is to have seizures?
Resigned to a life of medication
Side effects and memory loss
Hoping for the best
Fearing the worst
Hoping life will not end as a mere shell
All memories lost
Clutching to what little remains
In a frantic effort to save
Those last enduring thoughts
To retain some humanity
As time increases its cost
What life has become is loss.

Sarah DuCloux-Potter
Age 31, person with epilepsy

I try not to let seizures or epilepsy affect me anymore. The only time I was really impacted was at diagnosis and that was a looooong time ago. Then I was angry. Now it comes up then and again when I have to figure out a ride somewhere as I can't drive, but other than that I'm just another person who happens to also have epilepsy. I have partial complex seizures that can generalize. They usually happen in my sleep. I'm mom to Tianna, an awesome 12-year-old girl who started junior high this year- she really is the light of my life and constantly amazes me. I also have the coolest husband ever, Les, a preschool teacher who I love so much. Rounding out our house is our sweet cat Lolla who provides both laughs and affection. I work full-time in a job that challenges me and that I enjoy. I really feel like one of the luckiest, richest women alive.

Balance

A thin wire
teetering
so
close to the edge
can slip
fall
any time
knowing that
what's below
is sharp
dangerous
dark
even
unclean.
Walking on
the
line in
tiny
steps.
Wobbling, swaying,
attempting to

balance
just
so.
Trying so
hard
to
just
keep
from
falling.

IT

lipstick smeared
mascara running
faces falling
melting maybe even
falling apart
or am I?
falling, that is.
down.
whooshing, nearing
the ground
time-out
not hearing
jeering or seeing
the leering.
soon is the
comforting, the
soothing mixed
in with the
burning
memory
or lack of
it-
that is.

Angles

We walk through life
at an angle,
never forward or backward-
not even sideways.
It’s why things can seem so
down,
so up,
so all around.
We don’t really fall
or bounce.
It just feels that way
because we are
so angular.
The word
try
should really be ‘tri’
as in tri-angle.

Life.
It’s what it is.
It’s what it isn’t.
It’s what we have,
and
have not.
It’s flesh,
bone,
blood.
It’s so much more
than that.
Some would say
it’s indescribable.
Ah, but
they are wrong.

Life is life.
It includes all.
It includes nothing.
It includes air.
It includes death.
It truly
is an angle.
A triangle.
Walk it
and you’ll see.

When you’re up-
you’re up,
when you’re down-
you’re down,
when you’re at a cross road-
is it?
Really?
Nah,
just another angle.
Walk and you’ll see.

Peak-
peek-
peak
the triangle
tip top.
Ah,
but at the peak
don’t you have
to go somewhere?
There is no more up.
Ah hah!
Gotcha there,
it’s why the high
feels so so high.
Angles, my dear,
angles.

Down, we slide-
nope-
we don’t-
just another angle.
Life is oh so lovely,
oh so ugly,
oh so lively
isn’t it?
March the angle,
walk the angle,
run the angle-
it doesn’t matter,
as long as you
LIVE the angle.
And don’t forget,
that’s all it is.

You’re never really
up
or
down.
You’re there,
or here,
or everywhere.
Where time
is
nonexistent.
You are life in the angle.
Happiness,
depression,
boredom…
all belong here.

Without one-
there cannot be another.
Laughter,
tears,
chains,
freedom,
sickness and health-
we need them all to survive.

We cannot feel
if we don’t have a taste
of each.
Go ahead-
dance within the angle of life.
It’s yours to live.
So…what’re you waiting for?

Marilyn Halker
Age 73, person with epilepsy

These writings were written because I was very depressed by the diagnosis I had been given, because of the continuation of my seizures and the stereotactic radio surgery, and how my unplanned seizures would affect my family. So I began writing, and in writing, I was able to control my life. As I continue to have seizures, but now more infrequently, I find that I am no longer afraid. I realize that each minute of every hour is a gift. I do not worry about the ability to drive or not to drive. There are a variety of other ways to get around. I feel I have been more creative because of this.

A Neuro Angiogram

I lost my gamble.
The turbulence in my brain had continued.
This day that I hoped would not be needed
was needed.

A bearded man, exuding bundles of energy, appeared.
“I imagine you feel that I have not looked at your tests!” said he.
That is exactly what I thought and felt.
In that moment, I trusted this stranger.

The suspended black and white monitor
stares down at me.
The bearded radiologist teaches
his disciples in attendance
about me and the procedure.
I listen.
I try to learn.
I cannot.
It is too hard.

The bearded man snakes
the catheter to the expensive real estate
that controls my speech,
my comprehension.

Soon
all in attendance
file out.
“Don’t move!” “Don’t move!” “DON’T MOVE!”
I was told.

In that time
alone
my future with an AVM and
a seizure disorder is being determined.
I am not in control as I had been
for a long time.

Light on a Dark Place

Somewhere I read that if you have attained the age of fifty and have not had cancer or a heart attack, there is a high probability that you will live to the age of 92. One half of 92 is forty-six. I have now lived beyond that midterm mark, but not without incident. I have not yet had cancer or a heart attack. I do, however live with what some call a “bomb” and it is in my brain. The “bomb” is called an AVM, a contraction that sounds like a device developed by Strategic Air Command, rather than what it is: an Arterial Venous Malformation. AVM means that arteries and veins are joined in a defective way.

My malformation is located deep in the brain in the Wernickes area, the area that controls speech and comprehension. In my AVM, there are no intervening capillaries, the small blood vessels that connect an artery and a vein. In the absence of capillaries, nature had built up the malformed vessels to about the size of a half dollar.

I did not know that I had been living with this volcano in the eloquent area of my brain until about twenty-six years ago. At that time, no physician could ever find anything amiss. I still felt there was something wrong. I was told that dissociative seizures were probably the cause of my problem. I tried to learn to live with the excruciating headaches and tried to accept the diagnosis. That is, until the day my youngest daughter and I left to attend a family wedding. We did not attend that wedding. Instead, we ended up in the emergency room.

My daughter was fourteen. She had observed drivers using a clutch, but had no experience. She learned very quickly on that April afternoon on a busy freeway on the way to the wedding. She later told me that I had missed hitting several cars before I rolled my head back and started shaking. She did not know what was happening to me, but she knew she needed to save us and the people in the other cars who had the misfortune of being on the freeway at the same time.

While the electrical storm raged in my body, my daughter unbuckled her seatbelt, flipped on the right hand turning signal, and flung her whole body on top of my shaking body. Somehow, she down-shifted the car and eventually steered the car to safety at the side of the freeway, two exits from the entrance where we entered.

The medical community, at long last, diagnosed my problem. I had not been crazy. My seizure was caused by an AVM that had been there since I was born. I was so relieved that my problem had been identified. The fact that I could not drive or that I would continue to have seizures, or that the AVM could hemorrhage at any time did not bother me. I felt I lived by grace in the form of a fourteen-year-old girl who could not drive a car with a five-speed transmission.

Steven Ireland
Age 60, person with epilepsy

Both seizures and epilepsy have become part of my life in that I'll probably never go a day without being afflicted by a seizure and epilepsy. I've had to take the long and hard road to where thanks to GOD I have better control of my daily seizures and epilepsy than the other way around. I have complex partial seizures and will always have to take medication (24/7) to have any control over my seizure/epilepsy activity.

Epilepsy & My Life

My lifetime on the plains and hills,
With various types of seizures & seizure pills.

A natural life was difficult to come by,
Life had many a low & many a high.

My first seizures were hard to accept,
Later life became easier for me.

Epilepsy is not only a word to me,
Epilepsy is my lifetime you see.

Epilepsy Medication

Yes it is true for all goodness sake,
Most of us have epilepsy medication we do take.

Cost of epilepsy medication may run high,
Yet we all do truly get through it by & by.

Epilepsy medication may become part of our life,
Our taking epilepsy medication may become a strife.

Taking epilepsy medication all day long,
Helps all our seizures not become so strong.

We find epilepsy medication we all do take,
Yes, we should thank God for heaven’s sake.

“My Life with Epilepsy” is for all people who know and live a life with disabilities, especially people that have epilepsy. As you will read this entry seizures have been and will play a role in my life forever. To date I'm not a candidate for surgery, thus I'll have to be on medication for the rest of my life as well as seeing doctors, nurses, neurologists, along with taking tests and even going to emergency rooms and hospitals. My life as a person with epilepsy has been one of both medical and personal interest and through my entry I've tried to show both to the best of my ability.

My Life with Epilepsy

I've had epilepsy since I was born. Medically I wasn't truly diagnosed until I was five, although I've been both physically and mentally living with all types of seizures all my life. My everyday life is full of various seizures, various emergency rooms, various hospitals, and various doctors’ offices. Finally my life has been intertwined with my seeing various doctors, various nurses, various neurologists, taking various tests, and taking various medications and medication doses.

Yet with epilepsy, I've been fortunate enough to live my life with a strong family and friend’s network. I found out from my dad that in order to find and keep a worthwhile family and friend’s network I had to feel good about them as well as myself. I not only had to respect and appreciate other people and believe in them I also had to respect and appreciate and believe in myself as well.

My life has been full of various types of seizures and their activity. My epilepsy was never kind enough to tell me how many seizures I would have or when my seizure activity would start or end. So I’ve had various types of seizures at various times of the day. I've been embarrassed, ridiculed and even treated like a leper. Not knowing if any of them would catch my epilepsy, many children & adults treated me like a leper. I was young but I knew it was the 20th century and people are not going to catch my epilepsy by touching me or being around me. Unfortunately the technology, the doctors, nurses, the medication, the literature, the classes, or other programs were available when I was born.

I don't regret living with epilepsy in this timeline. I always will feel that I could have done better and since I can't go back to this time I wish to learn from it instead. My strength to turn my epilepsy to the advantage, of my controlling it instead of epilepsy controlling me, has come about in my later years. I've grown a strong religious bond as well as a strong work bond I formed my own positive solution. My solution is basic and always uses a cup half full. My life with epilepsy has been a fortunate one for many reasons.

I was fortunate to be born in a country where various types of disabilities were and are accepted. I was fortunate to live in a country that would help me with the cost of hospital bills and doctor bills as well as medication bills. I was fortunate to be accepted into the work force for everyday living and the cost of living. I was fortunate to be able to have a truly worthwhile transportation system. I feel fortunate to know there is not only a good communication system but also many emergency rooms, emergency vehicles, hospitals, doctors, nurses, neurologists, tests, and various medications & medication doses. I'll always have the rest of my epilepsy life filled with various medications, neurologists, tests, seizure activity. I'll always know that my life is full of many treasured friends as well as my treasured family network as well.

Tayler Johnson
Age 16, person with epilepsy

I was diagnosed with grand mal and absence seizures in December of 2006. I'm on the Anoka Twisters Dance Team and EFM's Youth Advisory Council. I don't let seizures stand in the way of achieving my goals!

Just a Distant Memory

I walk into the locker room.
I could tell you what I've experienced here.
I close my eyes and relive that moment,
even though I only remember the end.
I could tell you of the tears I cried.
The questions I was asked.
How I was in an ambulance.
They kept me talking,
entertaining me with questions.
More so they were entertained
with my answers.
Situated in a room,
white walls surround me.
Enclosed by
beeping machines.
My eyelid looks like I have
maroon makeup on.
I feel it, feeling a slight sting.
I leave it be-
it isn't my main concern now.
Staring at the ceiling,
tears still mask my face.
Comforting words fail.
Hours pass and I finally walk thru the doors,
eyes examining me to see what happened.

Holding onto my dad and brother,
I ignore the stares and wish for my bed.
My eyes open,
I feel my eyelid.
No marks, no scar.

Just a distant memory…

365

For 365 days,
the clock has mocked me.

For 365 days
of passing over road bumps.
365 days later,
the clock has gone silent.
365 days later,
all is well.
365 days down,
and a lifetime to go.

Kay Irving Kramer
Age 71, person with epilepsy

I am a 71-year-old retiree from 32 ½ years with Honeywell. I served with the Council of Honeywell Employees with Disabilities; Honeywell Corporate Diversity Council; Epilepsy Foundation of MN; Honeywell Corporate Representative to the President's Committee on Employment of People with Disabilities (teaching businesses how to adapt to the Americans with Disabilities Act); Human Rights Commissions of Crystal and New Hope; and League of MN Human Rights Commissions; as well as being Past President of St. Therese Residents' Council. My collection of poetic verses is entitled, "The Rhyme and Reason Works of Kay I. Kramer." My verses were written to be inspirational in respect to the items they refer to--from family, life, and nature, etc.

Disabilities

Many people throughout the world, both have and face what we call disabilities,
Yet, they each go on every new day of their life, to do as much as
they can and seek to please;
Some disabilities are virtually harder to cope with than are others,
And sometimes their occurrence can cause one's hope to become
smothered;
Yet, at this time I do frankly say,
"You must have and practice faith and maintain hope throughout
the course of each new day;"
Realizing all too well that sometimes we cannot do things as other do,
But with the use of perseverance we can achieve our goals too;
We often tend to learn and accept the hardships that these things impose upon us,
Since, we realize that they are but a part of our life and if ignored,
can cause depression or strife;
And while many may speculate on one's ability by what they hear or see,
They know not the truth of mind and heart of those with a disability;
So, however hard your disability may be seem you,
With faith, hope and love you'll succeed in life too.

Composed and written into the
Rhyme & Reason works of
Kay I. Kramer, 2/9/2009.

Friends

We come to make friends throughout every stage of our life,
From our childhood years and during life's course;

They're often there in times of need, or to help us out,
Yes, a friend can often assist us in nearly everything we face;

And as we grow older with our friends we grow to appreciate their
kindness and care,
When we need advice or a shoulder to simply lean on;

Friends are there to help us realize, bear burdens, and move on,
We often cherish our friends more than words can express;

But our actions, deeds, and respect for them is deep in our heart,
For with 'true friends' we know they'll be there in times of need
and will not part;

So, from the start to the end of each day,
Value them with love, respect, and consideration, I do say;

Also, in your daily prayers, especially at night,
Thank The LORD and bless your friends for giving you might.

Composed, written, and entered into The
Rhyme & Reason Works of Kay I. Kramer,
September 10, 2008.

The Beauty of Nature

Often when I awake in the morning, I see the pretty and bright blue sky,
Coupled with the warmth of the sun that catches my eye;
Then later as I look out my living room window, I see the beauty of
nature, unfold it’s pretty image before me,
The trees of all types show their bright green leaves;
While the grass its splendor all around the front of my yard;
And many pretty flowers show signs of a rainbow along the
sides of the building in which I live,
Yet, soon the Fall season will be here, and many of nature’s colors will
come to disappear,
But the beauty of nature will always be with us in its own way, be
it summer, fall, winter, or spring I do say,
It’s been that way through the earths many years of life and will
continue to grow and flourish when we're no longer here,
Yes, "The Beauty of Nature" brings warmth to my heart with
everyone of its elements from each days start.

Entered into the Rhyme & Reason Works
of Kay I. Kramer, September 7, 2008.

Coping with the diagnosis of epilepsy

Throughout our lives we have an ability to do, learn, participate, work and partake of life's many virtues.

However, when you have, or have been diagnosed with epilepsy, it may seem like the roof has fallen upon you and your desires in life. It's easy to recognize at this point that you may come to feel different from others who don't have epilepsy; you may feel a degree of over protectiveness, by parents, family, school, employer, or even friends.

The first and most important item for you to undertake is to begin to learn about yourself and the situations that can worry you, raise anxiety levels, and trigger seizures. With this you have to take a close and personal look at your likes, dislikes, worries, fears, when to take medicine, and of course learn your limitations--The degrees of energy that you can physically or mentally pursue without overdoing it and bringing yourself toward the threshold of a seizure.

You must realize that we are all different and essentially one size doesn't fit everyone, except in a doctor’s interpretation of findings diagnosing your cause of epilepsy. What affects one person, may not affect someone else in the same way.

To learn and understand about yourself and epilepsy more fully, I believe it's often helpful to pick up and read a simply written book or pamphlet on what epilepsy is, joining a support group or contacting your local epilepsy foundation office is another way to attain insight on this.

Chances are that you are going to have to work harder to pursue your desires, be they education, participation, or work--because essentially many people still don't recognize or understand the factors associated with having epilepsy. That creates more pressure on you in your personal efforts to do and achieve the things you desire.

Also, in learning about epilepsy, it is significant to recognize that as you grow throughout your life, from childhood through adulthood, your body itself is changing to try and meet its demands at those many stages. With that, certain things you undertake may become more difficult, or medicines may necessitate change, so as to provide you with as full a degree of stability as is possible in your case.

Last, but not least, one item I found significant throughout my entire life of nearly 70 years now, is to be as open as possible with those who you regularly come in contact with by establishing a dialogue with them, so that they can come to understand you better, learn about epilepsy, and be aware of your understanding, relative to your management of your condition.

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.

L. E. LaRue
Age 36, person with epilepsy

The inspiration for the written work is my life. I liked being able to help out those who needed it after wondering for a while how I could. Epilepsy affects my life a little, but not too much now. I'm thankful it never was serious enough to prevent me from getting a driver's license. But it wasn't easy living with it, knowing so little about it for a long time and of course fearing rejection from friends when I was younger. So I didn't tell them about having epilepsy. I was diagnosed with epilepsy at age 4 and was on Dilantin until I was 10. Seizures are not too frequent now, about once a year or even less often. I lead a fairly full life, though I am still single and sadly I know how true it is how those with epilepsy have a harder time when dating. At least if I fail now when dating it's no longer due to lack of trying.

Mentoring

The concept of mentoring has been around for a while. I know this from reading the dictionary. The first definition listed it as a proper name, as Mentor was a friend of Odysseus (from Homer's Odyssey which I read in high school) who was entrusted with the education of his son Telemachus. The second definition, the more common one, arises from it: trusted counselor or guide, tutor, or coach.

The past year reminded me of an important fact in my life--I participate in various mentoring programs. I feel good about the contributions I make while there. Soon I will be starting my fourth year in a mentoring program through my employer, where we partner with a Minneapolis high school. But it's not the only one I've done--in June I volunteered at Camp Oz through the Epilepsy Foundation for the first time. I will cover Camp Oz first.

I had heard of Camp Oz for a while, due to attending support groups regularly. I had wanted to volunteer before, but waited too long to express interest--not enough time to pass a background check. So I made sure to ask about it earlier this year. It was no problem passing the background check; the most I've ever had on my record was parking tickets and minor traffic violations. I said to the volunteer coordinator I was willing to do only one day as I needed time off from work to be there. I asked what day I was needed most and would be there that day. This happened to be Friday, the last day of camp. It was nice to know the camp is a short drive away, across the river in Hudson, Wisconsin.

I arrived in the morning and checked in to get the information I needed and was assigned a camper. I did the best I could when shooting baskets with him but it was hard to know what to do when informed he couldn't talk. I liked being reassigned and was still on the basketball courts. There were plenty of kids coming in to shoot baskets, and I liked hearing their stories. I am sure they liked having somebody listen as well.

Apparently many of the kids had disorders besides epilepsy. One kid told me about having autism. He sounded articulate when he spoke of favorite subjects like Disney movies. It reminded me of a lesson taught in a favorite movie of mine, "Rain Man". People who struggle with a disorder like autism or epilepsy can still be high-functioning people. While much of my time there was spent chasing down basketballs that had bounced off the court, I liked how it kept me busy and I did do other things. I liked being included in some of their basket-shooting competitions and it meant being vigilant. One camper came to me with a cut on his hand, unsure how it happened. So I went with him inside to have him see the nurse. I stayed with him while the nurse worked on him and advised him to try to avoid scratching it after the bandage was applied. I liked how my instincts kicked in--when somebody comes to me looking for help, have solutions ready. If I don't have the answers, send them to who does.

I wanted to remember my time there that day and I did take four pictures. First was the sign from the road, reading "Camp St. Croix". Second is of the basketball court. Third is a banner, celebrating the camp's centennial in 2009. The fourth is of some sidewalk chalk artwork. One of the kids proved to be quite talented. He did detailed drawings of a flower with many petals on it, along with an arrow through a heart. Some of the camp coordinators noticed it and said we should tell his family about the art contests available through the Foundation. He even drew one image after I described it for him. I was thinking of theater masks I had seen before, one laughing and the other crying. He said it was called ‘laugh now, cry later’ and drew it really well like the others.

At the end of the day I helped with packing up supplies and putting them on the truck going back to the Foundation’s offices. I found out this was why I was needed the most on this day, since few wanted to do the heavy lifting. I truly liked being part of it all, a reminder of my younger days at a summer church camp, including having lunch with the campers. I’m sure I will have the camp shirt I was given for years to come.

I like doing the mentoring program through my employer, but it is definitely challenging to mentor a high school student. Most of our contacts are by email, and in previous years I would get plenty of brief messages or no responses at all. But it was a little better this year. It is called the Roosevelt Mentoring Program as we partner with Roosevelt High School in Minneapolis. The student assigned me this year said he had played football, but since the program officially started in November--after the season ended—I didn’t see him play at all. I like how he attended all of the events, such as the zoo in Apple Valley in January and the year-end event at Augsburg College in Minneapolis in May. I’m unsure what I taught him, but he did teach me something I needed to learn. There was a motivational speaker at an event in March and I talked to her for a short time after she signed the book of hers I had bought. I was late on having lunch and he started without me when he couldn’t find me. It taught me a valuable lesson: there are others who need a mentor now more than I need one! Don’t know why I keep ‘dangling the carrot’ in front of me, unless it’s because the familiar is comfortable. I had submitted artwork to the Foundation for an art contest, inspired by advice that a former boss and mentor had given me: be your own role model. Because of this mentor, I am stronger now and have less of a need for a mentor as I did my best to follow the lessons I was given. I don’t hear from this mentor much now, but these lessons are still with me. I am thankful for the patience shown to me, not giving up on me, along with being positive and encouraging. It reminded me how it is best to do the same with others as you only get what you give in life. It sure is better than the alternative, believe me I know, having grown up in a cauldron of verbal abuse.

The third notable mentoring opportunity was a back to school shopping event through the Salvation Army. At the end of the morning I sent my student back on the bus and said “you’ve got some good outfits there.” It was a good feeling when I taught him what I know, like how it is best to try on all of the clothes to see they fit. If they’re pants, walk in them a little and see how they feel when you’re sitting down. It made me think of Whitney Houston’s song ‘Greatest Love Of All’ about the importance of mentoring: “children are the future, teach them well and let them lead the way.”

While the highlights of the year include the mentoring I did, I still did plenty of other things I enjoy like traveling. Physically and mentally, I am fine and thankful for this as well. The spinal cord injury is stable and bothers me less often, so I need to use Lyrica less for the pain. Losing 25 pounds after doing a company-sponsored weight loss program helped. I think my physician had recommended weight loss before. My neurologist, Dr. Usmanova, approved a cutback on appointments to once a year; previously it was twice a year. The online dating venture hasn’t panned out yet, but I’m still trying and learning which is most important. It’s discouraging to go through so many quick rejections, but I’m not letting it stop me like before. Since most matches don’t progress very far, most don’t hear about my history of epilepsy. This is fine with me. I still only tell my dates when the time is right and when I’m comfortable with it. This is why a good friend of mine from work is still one of the few that has ever heard about it, as I want to be accepted first.

It was a year of beginnings, as I started a blog since I enjoy writing. I decided this was a good way to get my writing read by more people. Fate intervened, although the reason shouldn’t matter much, as at least I got started on a blog, finally. The unpopular decision to close a school in my hometown was what motivated me to get started on a blog. The school was named for one of my inspirations as a writer, Emerson Hough, an author of western stories and historical novels. He is likely the most famous person to come out of my hometown of Newton, Iowa, so it was like throwing one of our own under the bus when closing the school. I started researching Mr. Hough online and educating myself.

Writing about my findings felt good as I was sharing what I learned with others. I do write about various subjects, such as my everyday life, but Mr. Hough is still somebody I write about every so often. It feels good to do something I'm good at and enjoy, and I also feel this way when doing open-mic comedy. It's nice to be willing to try out a new skill and master it. As long as I have my talents, I will be fine.

Jean Manrique
Age 54, person with epilepsy

I was diagnosed with epilepsy two years ago and continue to have frequent simple partial and complex partial temporal lobe seizures. My life has changed quite a lot in the past two years - I am no longer teaching junior high Spanish, no longer drive, and never know what the next day or hour will bring. But I am beginning to learn to live in peace with my seizures. I have more time to write, knit, read and think and have learned to take each day as it comes and be thankful. Writing has always been my response to most everything in my life and has been an essential part of learning to live with epilepsy.

no trucks today
october 11, 2010

"fire trucks!"
he stood before me
waiting
brown eyes on my computer
entreating smile

we met at the coffee shop
have become friends
have a ritual
of watching fire truck,
sometimes garbage truck videos
on my computer

his parents sit nearby
enjoying a quiet cappuccino

i've learned about trucks
even like the videos
and especially my new little friend,
my own two boys grown

but today i could only stare at him

i wanted to greet him

open my arms
help him into my lap

but i was frozen
trapped

his father knew something wasn’t right

i tried, so hard, to explain
tell them i would soon be fine

but my rebellious brain was in control
had me in its grip
wouldn’t let me speak

when the seizure passed
and my weak legs allowed me to walk
i went to him
told him i was sorry
we couldn’t look at trucks today
said i wasn’t feeling well
but soon we would
have another chance

he was disappointed
didn’t understand

i feel the exact same way

nocturnal seizure
10-5-09

sinking ships appear in my dreams
waves crashing out of control
shores
houses
about to drown
cliffs crumbling
darkening skies

i’m on a shore
far from home
watching the skies
the waves

i’m in a house
it breaks from its footing
begins to float
to toss

in the roiling water
Dorothy’s house
swirling in the tornado
i’m on the glassed-in porch
at a loss

this world is ending
is there an Oz somewhere?

my stomach is churning
as the house swirls
my head is hurting
my brain is draining
away to another world
one i never remember later
can never return to at will

i wake
doubled over
doomsday still in the room

as the calm slowly returns
this world returns to it’s
secret place in my brain

i sleep again
powerless as the ships

ology
october 7, 2010

neurology is my brain misbehaving
tossing electricity to and fro

epileptology is 25 electrodes
attached to my head
trying to understand

seismology is the earthquake
in my body
arms and legs out of control

psychology is living with this
and learning to be content

Samantha Martin
Age 16, person with epilepsy

My name is Samantha Martin. I'm a junior at Groves Academy. Living my life has been the inspiration for my writing. I have complex partial seizures and when I was little, they used to prevent me from doing certain activities. But now that I'm older, I don't let them hold me back anymore. I just keep pushing ahead.

My Epilepsy

Sometimes I feel alone. Like no one else knows what I'm going through. I'm living in fear, never knowing when ***they*** will come.

Although I don't remember all the way back, I've been told that I had my first seizure when I was born. It scared my parents half to death. Supposedly, I didn't have any more until I was seven. One morning, my mom came in to wake me up and tell me to get ready for school. But I was having a seizure and that seizure lasted a long time and worried my parents even more. The ambulance came and took me to the emergency room. I remember everything….the pain, the fear, even what the people around me said.

That's the strange thing. I have complex partial seizures but I don't black out. I can remember everything. I can also use all of my senses during a seizure. I'm having pain during the whole thing. It's really annoying. But one time, my sister, Jackie said something funny and I started laughing during one.

Anyway, when I was in fourth grade I was at the horse barn, walking through the pasture to get the horse that I usually rode, and accidentally got shocked by the electric fence. (I know. Why would they have an electric fence for horses?) The shock caused me to have a seizure (of course). I remember that the horse that I rode, Queenie, came over to me. She watched me and I think she was trying to protect me because she kept the other horses away.

In fifth grade I was coming back from lunch break during school. I walked up the cement ramp to go to class when my arm started shaking. I was hoping I could get the door open before my seizure got too bad but, of course, that wasn't how it turned out. When I finally decided that I wouldn't be able to open the door in time, I also didn't have time to sit down. I fell. My head was the first thing to hit the cement (I know, ouch, right?) My teacher, Mr. Wick, came out and saw me. Luckily, he knew what to do (mainly because my mom and I had told him) and then he also called my mom.

In seventh grade, in California, I was in art class making a clay sculpture of a dragon when I felt a seizure starting up. The stool I was sitting on was kind of high off the ground, so when I tried to get off, I ended up falling. My legs gave out and I fell on the tile. There was cement under the tile. So once again, I fell on cement. Luckily, *again,* I didn't damage my head except for a bump.

I was playing kickball in eighth grade at Groves Academy (where I go now) when I got hit in the face by the ball. It caused a seizure (*of course*). My friend, Mike, ran over to help me. He has epilepsy, too, so it made me feel better to know he was there. He knew better than anyone what to do. It stopped and I literally clung to him for comfort. I felt weak again, and I knew that he probably felt the same way after a seizure.

One of my most recent seizures was at Home Depot. I was in the garden center and my dad was getting something (I don't remember what) for the house. Someone saw me and asked me if I was okay (*well, do I look okay?*) Then, more people saw me and they came over to help. I heard one guy say that I was "an epileptic". They were all really nice (as far as I could hear and see). Someone called 911, which I can understand. By the time the paramedics came the seizure had stopped. I was crying a lot and my voice was really slurred. It sucked, but I was still able to answer their questions.

Oddly enough, just as I was about to submit my story today, I ended up having my most recent seizure. I was sitting in the family room, working on this story and minding my own business when BAM! I started having a seizure. (Okay, maybe it wasn't a BAM , maybe it was more dun, dun, dun, dun, …well, you get the idea).

I called my dad who ran over and helped me get into a more comfortable position. It really didn't work that well because I just rolled over again. My dad was telling me he was there and that it was almost over (which I really appreciate. I do, really! But it doesn't really help). My dad called my mom and when she didn't come up he stomped on the floor. I even heard my mom yell something like, "I'm on the stairs!" When she got upstairs she ran over and checked on me. I heard my dad tell her that the seizure had been going on for a minute or a minute-and-a-half. She went to kennel up our dogs, get my meds out and ended up calling 911. The whole seizure was two-and-a-half minutes to three minutes. I was shaking and crying a bit at the end but when the paramedics got there, I was pretty much okay. The seizure had stopped and I was able to talk a little better this time. They took my blood pressure and put the little clip thing on my finger to take my pulse. They asked me questions like, 'how are you?' and 'when was your last seizure?' It all blew over pretty quickly. I felt perfectly fine after a half-hour. Then I went to the dining room to work on one the puzzle I started the day before…..it relaxes me.

All in all, my seizures are painful and confusing, but most of all annoying. Luckily, they are pretty well-controlled and I think I'm doing very well. I hope this little summery has helped you understand more about how I live with my seizures.

Suzanne Miller
Age 26, person with epilepsy

The thing that was the inspiration for my written work was the way epilepsy has affected my life so much and how I learned to deal with it. The person or persons that have inspired my written work are my parents, friends and doctors, because they have helped me with my seizures. I have had epilepsy ever since I was two years old. I have had grand mal seizures in the past and seizures that are so big, I end up in the hospital overnight. Other times, I just collapse and find myself on the couch, not understanding what happened. Since 2001, I had not had any seizures, but when I had a seizure while camping in Brainerd, I was scared knowing that it was my first one in eight years. Having seizures is no fun for me, but I can relate to other people and my friends now. I can help them out when they have a seizure and something goes wrong. I can go get help.

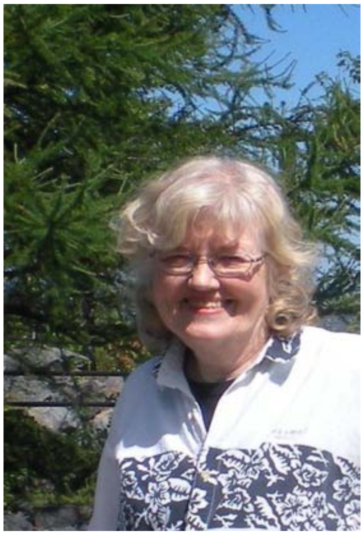
Suzanne Miller's Life with Epilepsy

My name is Suzanne Miller and I have had epilepsy and seizures ever since I was two years old. My parents had a hard time figuring out why I was dizzy and fainting when I was warm or when there was hot weather, so they took me to the doctor and they did some tests. They told my parents that I had seizures. I have had them ever since. Nobody else in my family has them. I guess I feel pretty special getting a great deal of attention when I have one. Summer is a big issue for me. When it comes to warm weather, I need to be careful and make sure I drink lots of water and stay cool as often as possible so I do not have one when I am outside. My friends and family have helped me through the last 24 years of my life, helping me control my seizures, as well as my doctors.

When I was a kid, my seizure doctor put me on medicine to control them because they were getting really bad. It helped for awhile, but they still were not under control enough, so he increased the dose and it helped a lot. When I became an adult, I began to see a new doctor and he changed my dose a little and that helped even better. I was seizure-free for almost eight years. But during the summer last year, I had my first seizure in eight years and it scared me, because I did not know what to do. I was in the bathroom brushing my teeth and fell to the floor. I found myself there after three minutes. My friends helped me through the issue and made me feel better. My mom and dad have been very helpful during my life and have always done their part, making sure I am in a safe spot to sleep after I have a seizure.

Sometimes my seizures are so bad I am in the hospital overnight, but it is not so bad because I know the doctors and nurses are there to help me recover quickly. My friends are always looking out for me when I am outside in the summer and make sure that I do not overheat too much. My boyfriend does not know that I have seizures, but people think that he should not know because it might make him worried or something. My sister has always been there for me when I need her when I have a seizure. When I have one, she usually goes to get my mom or dad. If she is not around, then my brother will pitch in and go get one of them. My dogs kind of know when I am about to have one because I am usually sitting on the floor next to them and they will see that and then go over to my mom or dad and nudge them and then they will ask me if I am okay. That has not happened in years and I am glad because I think that seizures suck and I think nobody my age or younger or older should have to live with them, but sometimes you just can't help that.

Being a Shining Star helped me realize what a great person I am and put my seizure issues aside and just be me. If a seizure does happen, just deal with it. Getting through it is not hard if you know how to handle it and have friends and family to help you and ones that care. I am glad I have such a loving family and wonderful friends that care about my seizure issues and know how to help me when I have one and try to help me if they think I will have one. Having seizures is no fun but I have lived with it almost my whole life and I do not think that will change, unless I get lucky in the future. Thanks for letting me share this story with you.



Sylvia Nelson
Age 70, person with epilepsy

I have been living with epilepsy for 46 years. I have grand mal and complex partial seizures. My inspiration comes from enthusiasm for life and using God-given talents to encourage others.

Epilepsy Mystery Resolved

A seizure lurks,
He wants to play a game with my brain.
"How dare you," I say,
"I'll not give way!"

This seizure continues his play and tempts my poor brain again,
"Go ahead, tempt me. You know I can win!"
The seizure bows low, he leaves my brain alone.

Thank you, Meds! Good job!
This time we have won the game.

Laurie Olmon
Age 43, person with epilepsy

A recent change in my seizures scared my family and me, which I had to put color or shape to somehow. Having seizures/epilepsy has been an amazing 30-yr trip for me. I have met amazing people, have gotten to be a part of an organization that is making a difference, help people along the way new to seizures. I have been diagnosed with right temporal lobe tonic clonic seizures. I want readers to remember that you are not an epileptic…..you are a person (an amazing person) that just happens to have epilepsy/seizures.

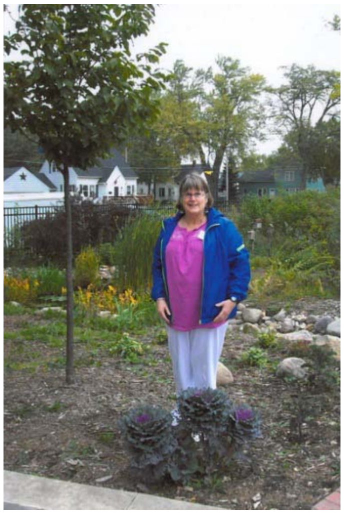
my fish bowl

it's been a little side note for 30 years or so,
a card in my wallet, a bracelet, necklace, of who to call or where to go
it's been a like a goldfish i must feed twice a day
but something replaced my goldfish and put a piranha there to play

it was not a subtle entry but a steady barrage of hits
i did not see it coming, hear the splash, feel the nips
it was a cruel evil thing with ferocious teeth and eye
it was done after eight attacks - on the bed - lifeless there i lie

my family came - rescued me never seeing an attack like this
my husband asking for my return but i was lost in the abyss
i do not remember that day - told only in story form
i do not recall the after - those are lost forgotten pieces torn
pieces like a patchwork quilt with greens and blues and reds
pieces mostly blacks and grays held together by a single common thread

i don’t know - evil finned thing came from where, why now, why change
i had come to terms with my goldfish, named it floppy, changed its water, fed it every day
but I fear this ugly animal - do not wish to call it mine
but this nameless tenant of the fish bowl thinks i am it’s - will be here for some time



Carol Oxborough Olson
Age 58, person with epilepsy

My personal experiences are my inspiration. My seizures and epilepsy drove me to desire equality. I wanted desperately to show everyone I could handle anything and everything that would come my way. I despised being different! My diagnosis is psychomotor seizures stemming from my right temporal lobe. This means my left side is affected. It is riddled with tumultuous activity during the larger seizures. My seizures range from petit mal, which can go unnoticed, to grand mal, where the whole body commences in violent shaking and banging around. Treat <u>everyone</u> as a person of value first. Think about their disability second, if there is one. Learn how to give any aid needed. Don't be too quick to call an ambulance. They send a large bill to the patient. If you can just bear the time out, the seizure will be over in a minute or so. Be sure to time the seizure. If the person does NOT come out of it in a short time, call 911.

Acceptance and Serenity

At age 14, epilepsy spoiled my world
A lot of bitterness & confusion unfurled.
At a time when most of all
I desired just to "blend in"
Instead I felt ostracized & recall
I drew lots of mortifying attention.
Countless unwanted questions were flung my way
But I didn't know what to say.
Like, "What's happening to you?"
Or "What are you trying to do?"
Things I didn't have answers for.
I wished I could simply slip out the door.

40 some years later as a chaperone I ride
On a special education school bus
With various ages of epileptic kids & I decide
Maybe the key for all of us
Is to ACCEPT epilepsy at every little bit
Not make a big bad deal of it.

Studying the topic to find answers makes you calm.
Camaraderie with other epileptics is a balm.
So don't hide nor try to be
    Inconspicuous.
You never will be free
    Or joyous
Unless you forget your possible strife
And start living your life.
Take on the responsibility
For all of this epilepsy.
Educate others & yourself too,
Find out how it affects all of you.

Dispelling the Darkness

"God, grant me the serenity to accept the things I cannot change." These are words that I should have applied to my life right after being diagnosed with epilepsy at fourteen years old.

"Courage to change the things I can." Meaning, I should change my attitude toward other people. Be patient and tolerant instead of bitter. Also, be thankful to those who were trying to be helpful to me in difficult circumstances. Be glad people cared enough to ask questions. This neurological disease takes its toll because no one can see your wounds. Actually, I should have been glad to research the questions to find the answers. Finally in high school I did write a theme paper on epilepsy. The chance to educate myself on this subject proved priceless. A seizure is caused by electrical impulses shooting off wrong in the brain. Everyone has these impulses. These are facts that do not vary. From this point on, things become individualized. This makes adjusting the right meds very difficult and time consuming. All of us have the tendency to have seizures. But only those of us with a lower threshold will actually fall victims. The threshold is equal to your brain damage. During the activity of birth itself, you are given 2% brain damage. A febrile or high fever incident will cause even more. Any head injuries and some diseases will too. I had a slight case of polio at two years old during the epidemic. My left side was affected and hung limp for a time. Was this the precursor to my epilepsy? Nothing is certain other than I must deal with the hand I'm dealt. I had known from the doctor that my seizures originated in my temporal lobe. That meant little. Come to find out, my right temporal lobe was responsible for any and all activities on my left side. In a seizure, different parts on my left side would jerk and contort relentlessly. It put quite a scare into any onlookers. I have seen some people having episodes. So I can relate to both them and the onlookers.

Many times, the person having the seizure will come out of it with a pounding headache and full of fatigue. Embarrassment seems to follow as well.
"And wisdom to know the difference." This prayer would have calmed me in times of stress and anxiety.

Thank you Epilogues staff! You give us

1. A night of camaraderie
2. A night of self importance
3. And a night that lends self worth.

Xandi Olson
Age 18, person with epilepsy

I have been living with seizures since I was six months old. Until recently, I had two to three seizures a month. Now, when I have them it's one to two a month. My seizures are intractable. I live in Mahnomen, Minnesota, on the reservation with two brothers, a mom, dad and two cats. My older brother and my dad have seizures too. I am 18 years old. I am going to college. I'm speaking for others who have epilepsy or other disorders who are unable to speak up.

Life with seizures

Sometimes it's just hectic. It has its ups and downs. Sometimes fun, but most of the time not. It's full of: you can't go. Maybe another time. Maybe we can go the next time. Maybe we can reschedule that. Then it's: Now you don't need this. I am always hearing different things at doctor appointments like, "no one said life would be easy or fair now did they?" Or, "keep your chin up kid." "If you don't succeed at first try, try again." Always being compared to others. Always having to prove your capabilities, maturity, responsibility, independence to doctors, your folks, other folks, teachers, pastors, yourself, programs. Or a bunch of other lame excuses.

It's fun when we do stuff with the youth group, with our families or friends. Church or Shining Stars. MEF, MEG. We have to go through lots of hoops too. For example, schooling, driving, trips sometimes even just our daily lives, daily tasks.

> Yes people with seizures are people too…we have feelings, thoughts, dreams, goals and futures. Just because we learn differently, at times think slower or sometimes are slower to react, see differently, process or tend to stutter or have different views, or not have the best coordination doesn't mean we can't do the same things other kids without disabilities can do. We can do the same things with help or modifications or just in a different way.

> We're tired of being underestimated, put down, and out-spoken. Life is full of cant's instead of can do's and always having to prove ourselves. We are sick of being teased/mocked. People thinking seizures aren't a disability and that all seizures are the same or that all people with seizures or some other disabilities are the same and can do the same things.

> Well we're not all the same. We are all individuals. We are all unique. We all have different personalities, disabilities, talents, likes, dislikes and different situations too. But we all probably got one thing in common: our disabilities and probably siblings that may or may not have disabilities.

Tessa Palmer
Age 15, person with epilepsy

I am inspired to write this poem based on my personal experiences with seizures. Honestly, I don’t know what my life would be without them. My diagnosis is Tuberous sclerosis.

Keep On Going

You hurt me like crazy.
You stop me from doing things I want to do.
But I keep on going forward.
I have to
go to a lot of doctor appointments because of you.
I remind myself that you changed me forever.
I don’t know how I would be without you.

Chris Poshek

Age 39, person with epilepsy and daughter has epilepsy

My daughter Hannah is the inspiration for my written work. Seizures have affected every part of my life. My two sisters, my daughter Hannah and I all have epilepsy.

Making a Difference

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 not make will always make us wonder. Did I or have I made the right choice? In "The Road Not Taken" by Robert Frost talks about the crossroads in one's life. **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 them as a back country road. The simple fact is we will all come to that fork in the road. When faced with a decision on my career choices, I viewed the possibilities and decided to make a difference.

My wife has never told me which career path to take. She loves me unconditionally. She would be there for me if I were a ditch digger. But she has encouraged me to take a path that will make me happy. Along the way to this current choice, I have one road that leads me to unknown destinations. It involves a bumpy path that included two tonic clonic seizures. It also was paved with dealing with my daughter Hannah's epilepsy as well. Now I am the crossroads. I am faced with re-educating myself. I know of a friend that is a teacher and I know she finds it very rewarding. And with the experience I have gained in working with kids with special needs, I know that this is some of the most rewarding work I have ever done. And my family only wants the best for me. They are here for support. But ultimately the decision must be mine.

The other path is familiar. My work experience has allowed me to learn a craft. That craft is lined with fried foods and thrilling adventures. Tomorrow I could walk into any food service environment and excel. But would I be making a difference? Would I truly be happy? A job in the food service industry again 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 dip and turns? And as I made my decision I knew the dirt road was the path I wanted to take.

As I sit here at a crossroads, I think back to my dream job. This dream job is filled with success as a sports announcer. This dream was filled with calling the big plays. This job would have fame and notoriety. Each day I would wake up and walk to my sports car. It would be cherry red and **shiny as a new toy on Christmas day**. I would then make my way to the big game and my delivery would be flawless. After the big game I would host a sports talk show that would make me the toast of the town. Then as the long day would close, I would retreat to my apartment in the sky and view the big city's skyline in all of its majestic views.

But my career path is much different than my dream job. I now know what I was meant to do. 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. I am currently attending Alexandria Technical College to get my general education degree. The next road will take me to Bemidji State to get my bachelors in early childhood education. And part of that road will finish with an emphasis in special education. I know that with this degree, I can go down many paths--an elementary teacher, a mentor or a special education teacher. 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, they 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 along the highway of life. I am fully aware that without my family and friends, I could never have been on the road to success. But as I look back on the paths I have chosen in my life, I know there is no right or wrong answer. I would not trade the sadness and pain I have gone thru to get to this point. All the roads I have chosen have led me to this very intersection. I am positive that I have the tools I need to begin this adventure. Some people would choose the superspeedway. But I’m choosing the back roads of the road that is not well traveled. So I’m popping in that CD, cranking up the music and ready for the greatest trip of my life.

Lisa Renee Ragsdale
Age 60, person with epilepsy

The “inspiration” for the poem is knowing that no matter how well the medications have the seizures under control, there is always a possibility that there will not be enough of the medication in my system to contain a seizure. Epilepsy (seizures) has changed my life permanently and forever and it is not for the better. I would give anything to have even half of my life back. The type of seizures I have are tonic clonic. I wish that I could actually go back to work full time with the knowledge that I could be on time every day and that the side effects of the medications would not affect my work performance. ----------.

Ellie

I live with Ellie.
She is always with me
She watches me like
  A loving mother
  But treats me more
  Like a sinister sibling
  Or an evil stepmother.

I live with Ellie.
She is always with me
And makes a point of
    Watching my sleep
    Patterns more than
    Anything else as she
    Likes to mess them up.

I live with Ellie.
She is always with me
  Day and night and night and day
  With little to no respect for my
  Actions or needs or desires, instead
  She waits for just the right moment
  To grab me by her trunk and slam
  Me into the closest wall she can.

I live with Ellie.
She is always with me
And even with all of my
  Efforts to keep her from picking
  Me up with her trunk, I know she
  Is ready and waiting and desirous
  To reach down and pick me up again.

I live with Ellie
The epilepsy elephant
She is always with me
And she always will be
I just wish she would go away

First experience

What is this?
I did not hear the alarm,
But I am awake
And I have my glasses on
Why would I be sleeping with
My glasses on, and do I see blood
On my glasses? Could that be?
What is this?
I get up and there is blood on my pillow
In my hair and, oh my god, all over the
Bathroom floor.
I think about this and think
I must have experienced a seizure
ok so it is time to call 911
I go to the phone and see that
I am still bleeding from my nose
As I dial the numbers
“Hennepin County Nine One One “ the voice
says inquiringly.
“Yes, um, I think I’ve had a seizure here
and have a little bit of a mess……”
“And you are…Lisa at…..?”
“Yes.”
By this time National Public Radio
Is on in the background only
I hear very little of it as the paramedics
Come in, pick me up, grab my keys and ID
And in what seems a matter of seconds
I am deposited among many doctors,
Nurses, medical personnel of all types
Within Hennepin County Medical Center
Not knowing, and yet knowing what this
Is all about.

Sarah Schmidt
Age 58, person with epilepsy

Never once did I hear the words, “You can’t do that because you might have a seizure!” Never once! This little city girl grew up, fell in love, got married, and left the city to start farming. Then followed three daughters, three sons-in-law, and grandchildren. To date, our dairy farm has interned 22 foreign exchange college students. I fill some spare time with volunteer knitting for the Mayo Clinic Chemotherapy Unit. How have seizures and epilepsy affected my life? Flip the question. How has my life affected my seizure and epilepsy? There! Feel the difference? Now the emphasis is on life. Creativity makes life much more enjoyable. Writing crystallizes thoughts. Music provides inspiration and peace. Art speaks volumes without words. In my life’s dictionary, the words “faith” and “hope” come before “epilepsy”.

Love not Bound by Seizures

If thou would ever leave me,
The night could hold no stars.
The heavy sun could never
Blossom into dawn.

But our love is like two candles
Whose flames dispel the dark.
The heat from each melts the wax
Into what only God can part.

Into thy strong hand I place my heart;
Thine other hand draw near.
That, hand in hand and side by side,
The future again is clear.

There Was a Young Lad

There was a young lad from Poughkeepsie

Who sometimes appeared a bit tipsy.

“You’ll be fine”, his doc said,

“If you just take this med.

“ For I think that you have epil-ipsy.”

Andrea T. Walker
Age 25, person with epilepsy

I got sober on January 3, 2009. An influential person in my life wanted me to write my story around drugs, alcohol, and getting and staying clean. I wrote this about the time of my 18-month sober anniversary. My seizures were a wakeup call that I failed to see. I could have died in a car crash – I had a seizure while driving. I didn't see how drugs and alcohol might have contributed to my seizures. The doctors said they didn't know what caused the seizures so I didn't connect the dots, and today it remains a bit of mystery as to why I have epilepsy. There are too many people in too many areas of my world to thank – epilepsy workers, my family and friends, and my Higher Power. I am grateful every day for what I have and for what you have done and continue to do!

I Couldn't Stop -- But Did

I couldn't stop.
People, places, and activities all revolved around use
Not even for hours
Could I control my use

Matt died February 15, 2000
My first using friend came the day after
We started drinking before school
And smoking weed after

Grandpa died August 3 that same year
Mom started drinking again
And hiding it from Ben and me

Couldn't play hockey that year; using was more important
Got a job to pay for weed
Skipped classes
Senior year I wasn't a full time student
Just enough to get out

UW-Milwaukee
Freshman year of college
Learned the Rubik's cube and how to drink beer
Played rugby, smoked weed
Didn't pass any classes second semester

Came home; didn't talk of Milwaukee again
Use continued day and night
Shows became my life
Camping in the summer, the Cabooze bar all winter

Before getting out of bed
Before going to bed
Use, use, use

I did school; I did life
While high

Bounced around from college to college
Got my AA degree
Had 5 seizures
Stopped doing acid

July 2005 to January 2009 was centered around
Use and using friends
Sold weed; they liked me
Shows all the time
Fake friends were making me happy

Somehow I thought this was normal
Smoking weed all the time
Selling, shows, school as little as possible
To say I was doing something

Until Uncle Tim said
”Come to Vancouver; study up here”
He also mentioned
“You must be sober when you come”

That was the light bulb
My life was not normal
Use was too big a deal
Something had to change
Or continue to insanity

I knew I had to stop
Vancouver was my way
But stopping before I got on the train
Was an impossibility
I was trapped in the old way

Study abroad was my ticket
It was my way out
Stopping the old habits
Ending the old ways

New adventure
New place, people, and things
With a new vision for the future
I was on my way

4 months sober
Back in Minnesota
Where to live?
How to stay sober back in the old homeland?

Live with Mom
AA became huge

One day at a time
Lose the old friends
Lose the old ways

18 months sober
Life is so different
Living on my own
School, volunteering
New, real friends
Not dependant on drugs

Back to seeing music
I can hold weed
It feels so liberating to hold it
And pass it by

One old friend remains
She will be sober one day
Then we can be real friends again

My life is grand
Not wanting drugs or alcohol
Freedom from the past
Let go
To a new peace

God’s grace has touched me
And brought me back
The old me is here to stay
Friends with Mom again
She is sober now
We could only be friends with the program’s help

The AA program is huge
My Higher Power has guided me
One day at a time
Brings peace, serenity, and a love for myself
That I didn’t know could be there

Movements of Love

writings by family, friends and caregivers
of people with epilepsy

Audrey Colasanti
Age 51, son has epilepsy

The inspiration for my work comes from my two sons, Dom and Lou, who both struggle with health issues; one with epilepsy the other with a rare heart condition. I am constantly amazed by their optimism and courage in the face of challenges. I have been truly blessed. Seizures have affected our family in on-and-off spurts. The “mind” battle with epilepsy…the constant fears and uncertainties…are perhaps harder than the actual seizures themselves. The information I would like to share is that people with epilepsy are incredible and that perhaps there are hidden gifts behind the struggle. There is something that comes with epilepsy that heightens the person’s kindness, creativity and “soul”. I believe this with all my heart and at times have wondered if perhaps they are the lucky ones, not us.

Post-Ictal: When the Aftermath of Heartbreak Brings Insight

As I pulled my Audi into the ‘Arrivals’ lot at the airport my heart literally skipped through its caverns, giddy with anticipation, knowing my son Dom would be home from college within minutes for a few days of rest, comfort food and syrupy, idyllic moments I’d already created in my mind. I’d changed the sheets on Dom’s bed, made his favorite key lime pie, had pulled out the Yahtzee dice and popcorn bowl.

When we sent Dom off to Landmark College in Vermont, an academic haven for students with learning disabilities, but also 1,200 miles from our home in Minneapolis, it was a decision filled with both hope and angst. By Dom’s emails I could tell he was homesick. “Miss u guys. Tons.” His college workload was also getting the best of him. “Stressful day, Mom, but I can do this. I can. ”

As I watched other passengers come through the revolving doors I got a text from Dom that his plane had landed. “Be down soon. Can’t wait.” Elated, I read his message only to look up and see a glorious display of fireworks booming far off in the distance across the Mendota Bridge, a super nova bursting dazzling blues and greens into the night sky, mimicking my bliss. It was as if God had felt my joy and dolloped it with one more cherry.

But as I continued to watch other passengers come through the doors, hug their rides and drive off, one after another after another, Dom didn’t appear. I kept glancing at his text. “Be down soon.” I waited and waited. “Where r u?” I texted back. No reply. I tried calling. No answer. On my fourth try someone finally picked up the phone, but the voice on the other end wasn’t my son.

In that single moment that a paramedic told me Dom had had a seizure as the plane taxied to the gate my euphoric high avalanched with the next hours blurring before my eyes; waiting anxiously by the curbside with a policeman, fumbling with my phone to reach my husband, watching my son being brought out in a wheelchair, ashen, slicked in sweat, lost in post-ictal confusion, a debilitating migraine and intense fatigue, the policeman pushing gawkers aside, the paramedics telling me, “It’s up to you. We can take him to the ER in an ambulance or you can do it.”

As with most seizures, Dom couldn’t remember what had happened. Snippets came out, slurry-speeched, groggy, and strangely, in third person, as if he were an observer to the event from afar. “There was a guy sitting next to me, Mom, who needed an oxygen mask. The doctor on the plane couldn’t find batteries for it and kept yelling down the aisle to the passengers… “Check your pockets! Look in your purses! I need double-A batteries! *Fast!”*

Dom also later told me about a dream he’d had while on the plane, but I suspect it wasn’t a dream at all. “I was falling and falling into an endless pit, trying to grab onto vines to stop my fall.” His teeth had clamped down so tight into his jaw during the seizure they imbedded deep purple teeth marks into his tongue.

Over the next forty-eight hours Dom alternately vomited, slept and went through a perplexing super-heightened state of awareness that we had seen after other seizures he’d had, where his mind burst into brilliant places not many of us will ever be privy to; remembering minutely detailed events from when he was just an infant and talking, at racer’s speed, in deeply intellectual and eloquent tones, ones not usual in his learning disabled repertoire. When we have mentioned this confounding state of lucidity to doctors they have met us with blank stares, not able to summon up the textbook that talked about such things.

Despite its unknowns, there is something magical behind the world of epilepsy. Vincent Van Gogh painted his most accomplished pieces during his most profound seizure states. Julius Caesar had seizures. So did Napoleon Bonaparte, Agatha Christie, Lewis Carroll, Lord Byron, Dante, Charles Dickens, Richard Burton, Socrates and countless other distinguished, creative minds. In some cultures, persons with epilepsy are thought of as deities and gods. But when a seizure hits, arriving unannounced at airports, at movie theatres, at the dinner table, sending strong electrical currents exploding through the brain as the body involuntarily jerks and jolts in response to the brief surge pluming in the cerebrum…we forget that there is intrigue behind the disorder.

Instead of the wonderful weekend I had envisioned for our family we spent it grief-stricken and shell-shocked, nursing Dom back to good health. But then I was reminded of the other hidden gift behind those with epilepsy, beyond the unexplained glimpses of genius. I had gone down to the kitchen to find some Jell-O, something that Dom could swallow through his ballooning tongue. He had been home for three days now and still hadn’t eaten. Stifling a sob, I heard footsteps behind me and turned around to see Dom himself, still pale, wearing his flannel pajama bottoms, walking weakly toward me with his long, gangly arms stretched out wide. I could tell by the look on his face that his Einstein-thinking and seizure symptoms had waned. Through his swollen, bruised lips he smiled and leaned in to me, saying softly as we held each other tight, “Mom, we never got our chance to hug hello.”

I knew then that the beautiful fireworks I’d seen that night as Dom’s plane touched down had in fact also been bursting inside of him; firing once again the unique brainstorms that could light up the world with their gentle grace.

Carrie Edberg
Age 33, son has epilepsy

My son, Garrett, has inspired me to enter the Epilogues Writing Collection. He had his first tonic/clonic seizure at 1.5 yrs of age. At that time I was working as an RN with many kids and adults that have seizures. But when it is your child and their first one I broke into tears and my adrenalin rushed. After having the doctor in the ER diagnose him with febrile seizures I was a little skeptical. I felt he only had a low grade fever and it was most likely from the seizures. In the next couple years Garrett had a few more tonic/clonic seizures…and yes the doctors still called it febrile. After asking and seeing many specialists I finally got someone to listen to me and do an EEG. It was then, at the age of 6, that Garrett was diagnosed with generalized and focal seizures. He also had many episodes of absence seizures daily. He is now on medication and checked routinely. I am happy to say that Garrett is doing well and seizure-free for a year.

Two words:

ON-EDGE
On-edge
On-edge
On-edge
On-edge

Carrie Edberg- mother of Garrett who is 7yrs who has generalized and focal seizures since birth.

Angela Halverson
Age 38, son has epilepsy

The inspiration for my writings is, as always, my beautiful boy. Evan has Respiratory Chain Mitochondrial disease, and with it, Lennox Gastaut Syndrome. "the sunshine between storms" represents the little things that most people take for granted. These are the things that keep us going when things are difficult.

the sunshine between storms

the sunshine between storms is
    your smile, your giggle
    us snuggled up with a sweet bedtime story
    your soft, warm breath on my cheek
    as you drift away to a peaceful place

the joy amidst pain is
    a joke shared, a long hug
    a favorite song sung while holding hands
    and you asking me to sing it again, sing it again mom

the peace amongst chaos is
    a walk through the leaves, quite times shared
    our nightly prayers
    and a faith that always returns after wavering

the comfort when we feel alone is
    a loving family, prayerful friends
    knowing that God is holding us gently each day
    in the palm of his hand

Lenten Meditation

Tonight's reading comes from Romans Chapter 5 verses 1 through 5. "Therefore, since we are justified by faith, we have peace with God through our Lord Jesus Christ. Through him, we have obtained access to this grace in which we stand and we rejoice in our hope of sharing the glory of God. More than that, we rejoice in our sufferings, knowing that suffering produces endurance, and endurance produces character, and character produces hope, and hope does not disappoint us, because God's love has been poured into our hearts through the Holy Spirit which has been given to us." Here ends the reading.

Our son, Evan, was born six weeks early on January 24th, 1999. He was five pounds 14 ounces and although he had problems nursing at first and was a little jaundiced, everything seemed to be going okay. We were released from the hospital two days after he was born, and Jeremy and I excitedly, although a bit nervously, took our firstborn home.

Six weeks later, on the day that Evan was originally due, he suffered a brain bleed and spent the next three weeks in the hospital, fighting for his life. We were told he would never walk or talk, that he would never see or hear, or attend a regular school. We heard phrases like "massive brain hemorrhage" and "global developmental arrest". We were devastated and in shock.

The pain of the next few months and years was crushing. We went from having a happy, healthy newborn to dealing with seizures, feeding tubes, enough medication and supplies to stock a small pharmacy, and learning all about what it means to raise a blind child.

Instead of a tricycle, we purchased a wheelchair. Instead of vacations, we used our leave time for emergency trips to the ER and hospital stays. Instead of early childhood classes, we began the Birth To Three program for babies with special needs.

Jeremy and I adopted the “one day at a time” attitude and sometimes “one hour at a time” when things got really difficult.

Back at the beginning of our journey with Evan, I was often told by well-meaning people, “God doesn’t give you more than you can handle.” To which I often shot back, “Yes, he does—on a daily basis, I have more than I can handle.” I was angry and my faith was shaken. I often asked God, “Why? Why Evan? Why me? Why my family?”

But as time goes by, life has a way of working itself out. Things get more familiar, issues get resolved, and a routine is developed that becomes normal, even if it is far from how other people live. I stopped feeling like I was just barely holding my head above water and began to live a little. Miraculously, and by the grace of God, life went on.

And then slowly, I began to realize that there are lots of joys that come along with raising a child, typically-developing or not. The hopes and dreams I had weren’t lost forever, just modified a bit. We set goals and work toward them. We fail and we succeed. We learn as we go. But mostly, we have a better appreciation for just being. Not being the best, or the fastest, or the smartest, but just being who we are and who God made us. And the unconditional love that comes with that is like Heaven on Earth.

After a period of time I realized I needed help with this challenge that God has given me. I decided to start saying yes to just about every offer for help we received. We live in a great town full of wonderful, caring people; we have a large and generous family; we belong to a loving church, and we’ve been blessed with prayerful friends.

More than once, we returned home from the hospital to find our driveway shoveled or the grass mowed. One December, after a three week stay in a Saint Paul hospital, we came home to find a beautiful Christmas tree in our living room. Under it were tons of gifts that I did not have the time or money to shop for.

Food showed up in our fridge, money in our hands. When our dryer was broken, one showed up in its place. Our hospital care coordinator told me that her profession would be greatly diminished if others had the same support system we did.

I know now, without a doubt, that these gifts are gifts from God. His love shines brightly through the people who hold us up when we can’t stand on our own.

So far on this journey, Evan has endured one muscle biopsy, two spinal taps, nine surgeries, 17 ER visits, 26 hospital stays, and countless tests and procedures. He will be closely monitored by his team of doctors in LaCrosse, Saint Paul, and Madison for the rest of his life. Through all of this, I have learned a lot of things no parent wants to know.

I wish I didn’t need to know how to administer rectal valium to stop a violent seizure, or how to change a gastronomy tube. I wish I didn’t need to know how to manage a hip spica cast or how to use a Hoyer lift. I wish I didn’t need to have the nurse’s advisor line or Evan’s epileptologist on speed dial. I would like to not know the names of children we have met who didn’t survive their own brave battles.

But for as many things I wish I didn’t know, there are many more which I am grateful to know.

I know amazing doctors and nurses who not only take care of Evan, but of our family as a whole.

I know a woman who sent us gift certificates to our local grocery store every four months for years and years.

I know a friend who calls and asks if she can put us on her prayer chain when she knows things are difficult.

I know an eleven year old classmate of Evan’s who, when Evan is having a tough time with something, stands up in her own church and asks her congregation to pray for him.

I know a woman who gathered a team of people together to help us remodel our downstairs bathroom because we could no longer carry Evan upstairs for his baths.

I know that my husband will change the messiest of diapers, give 4 AM medications, stay overnight in the hospital with Evan so I can come home and sleep, and hold my hand and pray for me when I am too overwhelmed with emotion to get the words out myself.

And I know that sometimes God will give me more than I can handle, but God doesn’t give me more than He can handle.

Evan is now eleven years old. He loves music. He loves being read to. He loves rides on the four-wheeler, and he especially likes school and all of his friends there. Jeremy and I also have a three year old, Ellie Mae, who, thankfully, is happy and healthy and is a little ray of sunshine in our home each and every day.

I’d like to be able to say that my faith is always steady and sure. But it isn’t. We still have difficult times and I will always go through periods of being angry and unsure. I will always continue to ask why when something happens that I just don’t understand.

But I know that given a little time and a little rest, my faith always comes back to me. It is impossible for me to look into the eyes of my two beautiful children and not believe that they are gifts from God.

Amen.

Jerry Hartlaub
Age 70, son has epilepsy

The inspiration for this poem is my son who has matured to be a delightful, competent father. He is a treat to be with and kind to everyone he meets. The perfect college professor. It has been a bumpy ride for my son dealing with many medications for controlling seizures. I am very proud of him.

Renaissance Man

Plaintive memories of discarded tasks,
A future outside the mix.
Squinting at vistas while playing with masks,
Hating to be in a fix.

Foggy purposes escaped detection,
Seems a crime to hide.
Hillock pathways flaunting rejection,
Usually wanting a ride.

Tasks of import rise on occasion,
Need to get them done.
Routine necessities create invasion,
A game played and won.

Gobs of energy join agony mental,
Piano lessons meant pain.
Mustering excuses unsentimental,
Practicing waste a shame.

Past transgressions eventually fade,
In surprising style.
Now music created in a bright shade,
From keys struck awhile.

Lend him an audience plus open mic,
A vivacious Ph.D.
Happy to teach and forgetting flight,
Then beaucoup play to a tee.

To really enjoy must stay awhile,
Immense commitment has power.
Amazing blossoms each day piled,
The Renaissance Man has flowered.

Chris and Rachal Johnson
Ages 38 & 35, daughter has epilepsy

Our daughter Tayler inspired this poem. Tayler is 16 years old and was diagnosed 4 years ago. She has been seizure-free for a year and recently got her driver's license. We tell Tayler to life live to the fullest. There is nothing she cannot do. If there is something she wants to do we just help her accomplish it within her limits. Tayler has Hetrotopia. She was born this way and seizures did not start until she was 12. They do not think that she will grow out of it. She has generalized tonic clonic and absence seizures. EFMN has made a difference in our whole family's life. We are all comfortable with what Tayler has. She has grown so much with all the programs that you offer. Shining Star, Winning Kid and the Youth Advisory Council have given her the opportunity to accept everything and keep believing in herself.

Amazed

She was a little angel from the moment she was born.
We were amazed.
She was always on the go and never stopped until she reached perfection.
Again, we were amazed.
She had her first seizure. We had no idea what this meant for our beautiful girl.
But yet, she still amazed us.
She keeps going about her life. School, Dance and even driving!
And still she never ceases to amaze us.
We know she will go far in whatever she sets her mind to.
She never stops amazing us.
Tayler – Keep believing in your dreams and you will always be Amazed!

Chris Poshek
Age 39, person with epilepsy and daughter has epilepsy

My daughter Hannah is the inspiration for my written work. Seizures have affected every part of my life. My two sisters, my daughter Hannah and I all have epilepsy.

Hannah's First Day

The day had finally come. She had new backpack. She had her new sparkle shoes on. She was ready to go. The months leading up to this were full of excitement. She had been talking of kindergarten all summer long. My daughter Hannah began kindergarten and as I look back to when this all began, I can't believe how far she has come.

When I talk of Hannah, my emotions range from pure excitement to anger. The anger comes from being a parent. When you have a child, you want them to be perfect. But fate can deal you a different deck. You have two choices at that moment. One is you fold like a deck of cards, or you take what is in your hand. You tighten up your boots and stay with what you have.

The excitement comes from the little things she does. When we are reading a book and she says, "No, Dad! Eyes on the book, not on the game." These are the things I cherish the most about her. I love that she has compassion for other people. I love that she likes to say hello to everyone she meets. I hope she always carries that with her long after I'm gone.

The sadness I feel for her is when she can't understand why everyone won't be her friend. It is also what I love about her. She wants to be everyone's friend. That trait will serve her well in life.

When I think back when Hannah was first diagnosed, I wondered was I going to be strong enough for her. Could I help her enough? Could I set her up for success? I thank my wife, Sheila for helping me get her started on the right path.

As I look back on where she was at 12 months old and where she is now, I am happy. I know she will be as successful as she can be. She will be able to become whatever she sets her sights on doing. I know that my little girl is now a young girl. She scares me every day and she makes me happy every day. She evokes so many emotions. And I would have it no other way. But I know she will be successful. Because my wife and I want her to be. But more importantly, she wants to be.

She was happy for her first day of kindergarten. She was happy to see old friends and meet new ones. My little girl has grown up.

Vesper Fe Marie Llaneza Ramos
Age 28, cares for patients with epilepsy

I, Vesper Fe Marie Llaneza Ramos, MD am a Neurology resident in Omaha, NE. This work tells the story of one of my many memorable seizure patients whose lives are incredibly complex and intricate. I believe that psychogenic non-epileptic seizures are just as fearful and disabling as epileptic seizures, and there is a need for better understanding of these phenomena. I find epilepsy very complex and I know I have the benefit of a medical school diploma already. I write poetry to keep my sanity and thus my humanity. When I cannot do anything else, maybe it helps to put the story out there.

Love in the Time of Seizures and Pseudoseizures

I have had epilepsy
For as long as I can recall
I have accepted my seizures
The ones I know
The ones I have been told about
I have lived with them.

I have asked the question
What God allows this?
And I have found my peace
Through turbulent adolescence
The most embarrassing
Seizures-on-a-first-date
Moments.
I have lived with them.

And I have been loved with them
By parents who still dote on me,
Friends who swallow their own fears,
By a wonderful, kind and patient man,
And an adorable sweet daughter ,
Who strive to understand,
When I cannot.
I have lived with them.

Things were well
I took my medications
I did not get so fat anymore
And we had our second child
Born from me a beautiful boy
Loved by me.

Then they came.
A different type of seizure.
They came while I was holding my baby
And I nearly dropped him.
Oh my God!
My seizures nearly made
Me drop my baby!

I was so scared.
Fear and anxiety pervaded
A household with a new bundle of joy.

More and more,
The attacks came.
The neurologist raised my meds
Still they came
So I was shifted to a newer drug
More expensive
Still they came
And I could not go back to work
And we had two children now.

The attacks continued to come
--A weird feeling
I cannot describe
Then I am told I start flapping
A different flap
Then my usual flap.
Longer. Much longer.

Finally my neurologist
Puts me up for surveillance
So I left my family
For the hospital
With EEG leads on my head
And grime and glue in my hair,
I pushed the button
And I flapped
My doctor recorded them all
He said he could
Give me the DVD—
Allow me to see myself
When I could not see the world.

Would have been the end of it
I wished.
If only.
But my trusted doctor
Dropped me
The biggest bombshell.
“Some of the spells are
Nonepileptic”

“Nonepileptic?”

“Nonepileptic.”

They looked like a seizure
But they are not?

I have real seizures
And I have fake seizures?
How the hell do I tell?
Do I spend my life with
EEG leads in my hair?

I look at my husband
I see
He is just as perplexed as me
Struggling to appear composed.
He has loved me
Despite my epilepsy
But what if…
What if I nearly dropped my baby,
And I could not blame the epilepsy?

What kind of a mother,
What kind of a person, am I?

I think of killing myself
Matter of factly so,
To end the agony of this abyss
Of no control
Of not knowing
Of simply being lost.
Maybe this is why
They had me seen by
Psychiatry.

I stand at a precipice
A moment in time
I am hyperaware
To the contrary of a seizure.
I look out.
I have a choice
Go home and live with this
Or go and rest in peace.

But what peace is that
Knowing I will be passing on
This abyss of no control?
My daughter will cry
My son will be lost
My husband will blame himself
NO!

And that is how I know
That I will go on
This new battle
Against the seizures
And the not-so-seizures.

I will have to live with this.

My husband gives me
A gentle touch at my back
“Are you ready to go home?”
I nod.

I know we will talk
For a very long time
When the kids are asleep tonight.
I close my eyes and pray
I have to be strong.
I am strong.
I have lived with epilepsy
I will live with nonepilepsy
And I will say
I have lived with them
I have loved with them.
With all that I am and I am not,
I loved with them.

My husband smiles,
My daughter jumps up and down,
From a distance, I swear
I could hear my baby laugh,
My breast milk starts to pour
Like a gate opened,
And I feel the love,
For all that I am and I am not.
No pseudo’s there.
No question there.