

Lexia: Undergraduate Journal in Writing, Rhetoric & Technical Communication

Volume III

2014–2015

On Dealing with Life

Dylan Owens

James Madison University

My grandfather came into this country in 1989, in the wake of the collapse of the Soviet Union. He was already in his late forties, so it was tough to learn English and start over from scratch, but he worked hard and ended up creating a pretty good life for himself. He was very smart, read a lot, and was always up to date with current events. He saved lots of money for his retirement, which he had planned to spend traveling the world with my grandma. He always came to our house hungry and argued with my parents about politics until the food was ready and we all sat down and agreed to talk about something else. I remember him complaining here and there, as he sat on our patio drinking tea or in front of our television watching football, about a subtle muscle weakness in his leg. Otherwise, everything was great.

One day, all that changed. My mom got a call from my grandma. She hung up the phone, shocked, and whispered something to my dad.

“What’s wrong?” I asked.

“Grandpa was diagnosed with ALS,” she responded.

“What’s that?”

“Lou-Gehrig’s disease,” she said, as if that would clear it up for me.

This was before the recent ice bucket challenge trend, where we all saw our friends dump buckets of freezing water on their heads, and nominate others to do the same or to donate money to the ALS association. Although it stirred some controversy here and there, the campaign was extremely successful, raising tons of awareness along with over \$100 million. All of a sudden, the disease gained national attention—everyone knew what it was and was willing to soak themselves to support the cause.

But that was later, after my family had been dealing with ALS for over a year. At the time of the phone call, I had never heard of ALS, so she had to explain to me exactly

what it was—*amyotrophic lateral sclerosis*, a progressive neurological disorder that takes away control over voluntary muscles, to the point that the patient can no longer breathe on his own, basically paralyzing him to death.

“This *sucks*,” my mom said, staring off into the distance.

“He’s 79 though,” my dad said. “He’s pretty lucky to be getting it so late. Most people get it much earlier.”

“That’s true. And he’s not going to die anytime soon.”

“That’s good,” my dad said, nodding. “Plus, there’s lots of research being done.”

They were both trying to be optimistic.

“But still,” she sighed. “It’s a terrible disease. It *sucks*.”

All I could say in response to this was a barely audible “Oh.”

Last year we had Thanksgiving at our house. We fried the turkey for dinner and invited our grandparents, who, as usual, came early, complained they were hungry, and initiated a political argument. We didn’t mention my grandpa’s diagnosis. He seemed perfectly fine.

The next thing we knew, he wasn’t fine at all. He was incurably ill and getting worse every single day. He couldn’t even get out of his bed and needed serious help just to eat or use the restroom. The money that was supposed to go toward travel was now going toward installing a chair lift, renovating the shower to make it handicap-accessible, and hiring a nurse to help take care of him on the weekends, so that my grandma could momentarily escape the house and her duties.

The most horrifying part about ALS is that, mentally, the patient is perfectly healthy, but physically, he is falling apart...my grandfather was falling apart. If you’ve ever slept on your arm and woken up with it numb and tingling and the only way to

move it is to lift it with your other hand, you might understand what this feels like. A prisoner in your own body—at least that’s how I imagine it. Except, of course, with ALS, you never wake up and shake off the unpleasant sensation. There’s no cure. You’re stuck like that for the rest of your life.

Last January, my mom drove my grandparents up to Boston to see if my grandpa could participate in an experimental study in which researchers would inject him with stem cells that could potentially replace his dying motor neurons. There hasn’t been any definitive proof of the procedure’s success, but at that point they were utterly hopeless and desperate to try anything. Even if the treatment didn’t work for him, even if it didn’t elongate his time spent with us by slowing, if not stopping, the spread of ALS throughout his body, he would at least be trying. He wouldn’t go down without a fight. Plus, he would be participating in research that could potentially prevent others from having to go through the same thing he was enduring.

Unfortunately, the doctors were very selective, and my grandpa was just too old and too far along in his sickness to be considered. We lost all hope.

I started college and was immersed in a busy life of school and tennis. Three months passed before I realized we hadn’t spoken, and I wondered how much worse he had gotten. I came back for Thanksgiving break and settled into the welcoming familiarity of my home. It was only when my grandma came to visit the next day—by herself— that I realized that my grandpa would never be here again, would never drink our tea or watch our television again. And at some point in the not-too-distant future, I would never see him again.

Since my grandpa couldn’t come to us again for Thanksgiving dinner, I drove up to Baltimore to see him. Just walking into his room and seeing the lowered bed and all

the strange-looking mobility contraptions was a shock to my system. It was also the first time I processed what my grandma must have been going through this whole time. Not only did she have to take care of a 200-pound body, which at that point had no voluntary muscle strength, she also had to deal with the powerful emotions of my grandpa's perfectly sound mind: his grief, his anger, his guilt, and despair. She had to take a leave of absence from her job, as tending to my grandpa became a full-time ordeal. And yet she didn't complain. I think it was because she already knew what I was coming to realize: that, even in the worst circumstances, people have to make the best of what comes to them. Sometimes life isn't about getting what you want; it's about surviving what you don't want.

Nothing my grandpa did in his life caused him to get this disease, and it didn't run in his family. ALS appears randomly, with no clearly associated risk factors. He had all these plans and all this money saved up for his golden years, which he had finally reached. And—bam—out of nowhere, his plans were shot.

There's a Russian adage that my mom translated for me that says, "A man makes plans, but then God reshuffles them." Maybe if I had come from a religious family, I would try to look for meaning behind all this, or at least an explanation for what my grandpa possibly could have done to deserve this. But since I can't turn to religion for strength, I just have to accept that in the reality that is our world, you can be walking a straight path, thinking that you're doing everything right because you *are* doing everything right—but then a completely random event can still come and add twists and turns, completely changing your trajectory.

In other words, shit happens.

Anything can happen to anyone, at any place, at any time. There doesn't have to be any rhyme or reason. All my life, I've been focused on getting good grades and getting better at tennis, constantly making long-term goals for myself. But now that I'm in college, I understand that I'm approaching adulthood, and I'm contemplating life beyond the immediate tasks at hand. Sometimes strength isn't about moving mountains, because there are just no more mountains to be moved. Sometimes you just have to trudge along your path, kicking aside one pebble at a time.