



Illinois Wesleyan University Magazine, 2002-2017

Volume 16
Issue 2 *Summer 2007*

Article 11

Summer 2007

Cherish the Time

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Recommended Citation

Neas Chamernik '91, Aimee (2007) "Cherish the Time," *Illinois Wesleyan University Magazine, 2002-2017*: Vol. 16 : Iss. 2 , Article 11.
Available at: <https://digitalcommons.iwu.edu/iwumag/vol16/iss2/11>

This is a PDF version of an article that originally appeared in the printed Illinois Wesleyan University Magazine, a quarterly periodical published by Illinois Wesleyan University. For more information, please contact iwumag@iwu.edu.

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Cherish the Time

In 2004, Aimee Chamernik '91 learned she had ALS. Today, she and her family embrace the precious moments left.



Story by Aimee Neas Chamernik '91

Illustration by A.F. Norling

“Can you still skate?”

My 9-year-old son Nick’s innocent question — posed on a brilliant summer day, a perfect day for in-line skating — stings my eyelids with hot tears I fight to hold back. My mind flits to a bird’s-eye view of a memory: Nick riding his bike and me coasting alongside him on my roller blades. My perspective shifts as I inhabit that body, my healthy body. I can almost feel the gentle wind in my face as we gain speed, coasting down the smoothly paved path in the park. I feel an aching lump rise in my throat.

Just as quickly, against my will, the image shifts to Nick on his bike and me careening wildly on my blades, arms flailing as I try to use my canes as ski poles to steady and propel myself. As it has hundreds of times before, my brain is trying to work out a way to make this happen. *There must be some way I can still do this, right?*

The truth steps in. I can barely keep my balance shuffling slowly along in regular shoes, let alone ones with wheels. I push the image of me on skates away. Can’t happen. Not anymore.

And it’s not about the skating. I really don’t mind that I will never skate again. Sure it was fun — great exercise, too. An activity that involved speed and danger (I never did learn to stop!), an edgy and thrilling diversion in an otherwise tame, suburban existence.

But it’s no big deal. No, what raises that painful lump, what threatens to choke off my ability to swallow, is how disappointing my reality is for Nick.

“Sweetie, I’m sorry. I can’t skate anymore,” I answer softly.

His bright, blue eyes blink twice; then he casts his gaze downward, his lips folding into a slight frown.

“Because of your ALS?” he asks, looking back up at me.

“Yes, because of my ALS.”

ALS. Amyotrophic lateral sclerosis. Lou Gehrig’s disease. My death sentence.

Nick hangs his head, swallows audibly, and turns away.

This is worse pain than I’ve experienced from any of my bruising falls. I can deal with the physical hurt. The emotional torment is on a completely different plane. The agony of *his* sadness — or 7-year-old Emily’s or, someday, 3-year-old Zachary’s — is almost unbearable. I am tortured by his realization that yet another aspect of our lives will never be the same.

As much as I fight to hang on to some sense of normalcy for our family, the truth is nothing will ever be the same. ALS will rob us — has already robbed us — of any chance at the future Jim and I envisioned back during our senior year at Illinois Wesleyan. Since we started noticing odd changes in my voice and a slight slurring of my speech four years ago, my body has begun a slow, inexorable decline.

It has moved from my throat and mouth into both of my legs, my neck, and my right shoulder, arm, and hand. It has destroyed my balance and exaggerated my reflexes — to the point that being startled elicits a reaction so violent my body collapses to the ground. It has left me choking and gasping for breath from a simple attempt to swallow water and has triggered such aggressive fatigue that it threatens to steal what little life I have left.

Eventually, with no effective treatments or cure, ALS will leave me paralyzed, a brain trapped in a body that no longer functions. If I'm fortunate, I'll have some type of communication device I can operate with an eyebrow movement or by blinking. (*Is there a workout video for eyebrows, so I can keep mine in tip-top shape?* I've wondered lately.)

In the end, even my breathing muscles will fail, and I will no longer be able to expel the carbon dioxide from my lungs.

And my kids will grow up without a mom.

No, this is definitely not the future Jim and I discussed at the library or during late-night Steak 'n Shake runs.

Which is why, even as I try to push it away, I so desperately cling to that mental image of me whizzing down the path on my blades, laughing with Nick as he passes me and I pass him back. Just for a moment, I want to fantasize. Just for a moment, I long to make that vision a reality.

I've done this before, and I'll do it again. I've visualized skipping, jumping rope, doing graceful dismounts off the bars at gymnastics — all made effortless, courtesy of my canes and a vivid imagination. My mind is a kaleidoscope, shifting and reassembling the broken colors and jagged images of my past, trying to arrange them in a new pattern — something different, but still beautiful. Still alive.

I sigh wearily, shrugging off the cloud that has settled over us, and put on my game face.

"You know, I can't rollerblade anymore, but that doesn't mean we can't still go to the park," I suggest to Nick. "You can ride, Emily can ride, and Zachary can either ride or Daddy can pull him in the wagon."

"But what about you?" Nick presses.

"I can walk until I get tired...then maybe I'll jump in the wagon with Zachary and really make Daddy work hard!" I smirk.

A smile flits briefly across Nick's face, fading before I'm certain it was there, as he considers this. "So you'll still go?"

"Of course I'll still go!" I pull him into a big hug. "I am not going to let this *stupid* ALS keep me away," I whisper fiercely, uttering the forbidden "s" word for emphasis. Given the circumstances, I rationalize, there are far more shocking words I could invoke than "stupid."

"Good!" he replies in relief.

* * *

Later I ponder again how quickly my thoughts shifted to rollerblading with my canes. The whole thing is ludicrous, and I know it. But as I face my bleak new reality, I refuse to give in to it. Sometimes — as in the case of the rollerblades — I lose the fight. At other times, though, I can find a workable substitute. Playing catch from a folding chair or tossing grounders in the family room, for example. And it's that spirit that allows me to go on.

I'm not naïve. ALS will win; it always does. At age 37, ALS took down Lou Gehrig, the Iron Horse, the legendary first baseman for the powerhouse Yankees teams of the 1920s and '30s and one of the strongest, most durable figures in 20th-century sports. In the 66 years since Gehrig's death, no major advancements have been made, and ALS continues unchecked, claiming the lives of about 5,600 Americans a year. It will surely show no mercy to a housewife more desperate than Bree or Susan or any of Wisteria Lane's fictional residents will ever be.

But I look at Nick, Emily, and Zachary, and I know giving up is not an option. As attractive as it sometimes seems to just pull the covers up over my head and hide, I know I can't throw away whatever precious time I have left. That is not what I want to teach them about how to deal with adversity; that's not how I want them to remember me.

So I strain the limits of my creativity, scratching and clawing to find any unorthodox approach I can to get the job done: dragging a blanket laden with Matchbox cars behind me like a sled dog pulling a load or carrying a notebook in my teeth as I crawl across the floor. Wedging my back against the doorframe of the van to lift Zachary from his car seat into the Target cart. It may not be pretty, but if I can find a way to do it, consider it done.

And if I can't ... well, that's when a sense of humor comes in handy.

As bizarre as it may sound, Jim and I have found humor to be one of our greatest weapons in battling this devastating disease. Throughout our years together — starting with our Cubs–Cardinals sparring in the kitchen of the Alpha Gam house and a flirtatious prank during an IWU phone-a-thon so long ago — we've teased and kidded our way through 15 happy years of marriage. Nothing eases tension like a well-placed one-liner. And somehow, if we can laugh about ALS, we can sneak back some of the power it has stolen from us.

Recently, Jim had been lamenting the fact that Mother's Day shopping for me would no longer be a piece of cake, not with Major League Baseball's decision to sign an exclusive deal that meant no more out-of-market games on cable. (This truly had been my favorite Mother's Day gift ever, allowing me to watch my beloved St. Louis Cardinals up here behind enemy lines in suburban Chicago.) But now I'd stumbled upon a new — albeit morbidly irreverent — gift idea.

"Hey, good news! I know you're really bummed that you can't get me the baseball cable package for Mother's Day, but I've found a new gift!"



Aimee Chamernik makes cookies with her two sons. Wanting to create as many happy moments as possible for her children to remember, she writes, "I know giving up is not an option." (Photos by M. Spencer Green/AP PHOTOS)

I feel a bit guilty as Jim perks up, expecting a serious alternative, but I forge ahead. I point to a page in a magazine with photos of Cardinals caskets and urns that are now available for the true “die-hard” fan.

“Nice,” he grimaces.

His eyes twinkle, though, and I grin back. We’ve reached an understanding that laughing at ALS is one way to reduce its hold on us. The more I can crack macabre jokes about my situation, the more I feel a sense of control. Outsiders would likely find it appalling, but our fellow support-group patients get it: I decide. I decide between tears and laughter.

* * *

I say all this now, four years after my first symptom, but don’t be fooled by my brash talk. It hasn’t always been this way. In fact, at this point, I see more possibility in each new day than I did when given my terminal diagnosis two-and-a-half years ago: September 8, 2004 — a date I now cite as readily as my anniversary or our children’s birthdays. Slurred speech and a weakened right hand and forearm were a nuisance at that time but not serious impediments. No, the worst obstacles were all in my mind.

The moment my worst fears were confirmed, my will began to crumble. I managed to maintain my composure in the neurologist’s office, even glancing at a stricken Jim and slyly goading him with, “See? I’m always right.”

But while flashes of my sense of humor — and a newer, darker humor — continued to punctuate the days and weeks following my diagnosis, I could feel my life slipping away.

Nothing had changed physically. My body felt the same on September 9, 2004, as it had on September 7. But on the day between, a mere three letters from the alphabet — A, L, S — had caused a seismic shift and left a gaping hole in my psyche.



Jim Chamernik (right) kisses his son Zachary in the kitchen where a “Strike Out ALS” sticker adorns the refrigerator. Jim and Aimee first met at Illinois Wesleyan; she calls him “my superman.” (Photos by M. Spencer Green/AP PHOTOS)

I continued to get up each day, shower, run errands, take care of the kids, go through the motions of my life. I strapped Zachary into his car seat to go get Emily from preschool; hustled the kids in the car to take Emily to gymnastics; stared blankly through the window as she jumped, twirled, balanced, and bounded around the gym. I listened in stony silence as the moms around me moaned about their carpooling duties. *What I wouldn’t give for more years of carpooling*, I thought bitterly.

It was all I could do to keep the wheels of our life in motion until Jim came home.

My weight dropped precipitously as I lost all interest in food and could barely choke down a few bites at each meal. Carry-out pizza, carry-out Chinese, carry-out chicken — it all tasted like sawdust.

The few times I made a feeble attempt at following a simple recipe, I wouldn’t make it past the pantry. We would inevitably be out of a key ingredient, so I would shut the pantry door and pick up the phone. Go to the store for rice? That seemed every bit as preposterous as going to China.

One evening, as I sat at my sister’s kitchen table after a visit to the pumpkin farm with our two families, I watched our kids playing Yahtzee and realized how empty I felt. Despite the laughter and commotion, the

clatter of the dice, the vibrant autumn colors, I might as well have been back at IWU in a darkened "Film Aesthetics" screening room, watching an old, black-and-white, silent film.

I was waiting to die.

But slowly, as day after hollow day passed, I began to feel restless. Dare I say it? The wait grew boring.

One day as I sat in the carpool line to pick up my then 5-year-old daughter from preschool, I decided a trip to the grocery store might not be as daunting as a trip to China after all. As Emily bounded into the van, she quizzed me about where we were going next.

When I shared my plan ("Someone I love very much has been asking for tacos and guacamole for dinner"), she squealed and bounced excitedly in her seat. Her wide grin and shining eyes stirred the embers of my soul, reigniting a tiny tongue of flame that had lain dormant for weeks.

In that moment I realized that I wanted to spend the rest of my life seeing that smile as many times as possible. And as I stumbled out of my fog over the next days and weeks, I clung to that image and my new mantra of sorts: *Life is making tacos*. Life is the ordinary moments that bring happiness simply because you're sharing them with someone you love.

And by that standard, I found I had quite a bit of life left in me.

* * *

In the last couple of years, I have narrowed my focus to advancing just two goals: making as many wonderful memories with my family as possible, and doing everything in my power to make a difference in the war on ALS.

While I'm realistic enough to know that any breakthroughs won't likely be in time to help me — the lag time from research lab to FDA approval practically ensures this — I am determined to do my part so that, someday, no other families will experience the devastation of an ALS diagnosis.

Part of that effort involves maintaining a Web site (www.askaboutaim.com) that provides a glimpse into my life with ALS and includes links to the sites of other ALS patients.

Why, with time running out, have I chosen to invest my dwindling energy in building this site? Because I hope to help educate a public that is largely unaware of ALS. Because 66 years after Lou Gehrig's death, the average life expectancy after an ALS diagnosis is still just two to five years. Because I want to dispel the frequent misconception — perpetuated in recent TV portrayals — that ALS patients are predominantly lonely, curmudgeonly, older men.

Because, as I write on my site, ALS patients “are like you. They love and are loved. They are husbands, wives, fathers, mothers, sons, daughters, brothers, sisters. They are ordinary people thrust into extraordinary circumstances.”

And, most importantly, because I hope to move others to join the fight — and to continue it when I’m gone.

Today, I can honestly say that my life is as rich and vibrant as it has ever been, with a sense of infinite possibility reminiscent of my experience in English Professor Pamela Muirhead’s Freshman Seminar. It was the most thought-provoking, difficult class I’d encountered in my sheltered, small-town life, and I relished the challenge.

Strangely enough, I feel that way now. I’m invigorated by the same feeling of being on uncertain footing, of no longer going through the motions, of being challenged to look at life differently and find meaning where I couldn’t see it before.

Did I undertake a liberal arts education at Illinois Wesleyan with a future as an ALS patient-advocate in mind? Obviously not. But I’m grateful for the ways I learned to question, analyze, and open my mind in my four years on campus. I treasure the lifelong friendships forged during those formative years and the college friendships that have been rekindled in the past year or so. I’m moved by fellow alumni who have joined me in the battle to defeat ALS.

Most of all, I’m immensely thankful to have had the chance to share my life with a devoted husband and father who I used to go out of my way to bump into on the quad on my way to class. I feel an unspeakable love for this man who sees past my disabilities and still sees me. I’m grateful for the unwavering commitment of a man who, today, would be more than willing to pull me in a wagon if I became too tired, just so we could enjoy one more moment as a family. While I may not be able to experience our outings on rollerblades anymore, these wonderful family moments still make my spirits soar.



“ALS patients are like you,” writes Aimee Chamernik, shown above visiting her son Nicholas at his elementary school. “They are ordinary people thrust into extraordinary circumstances.” (Photos by M. Spencer Green/AP PHOTOS)