



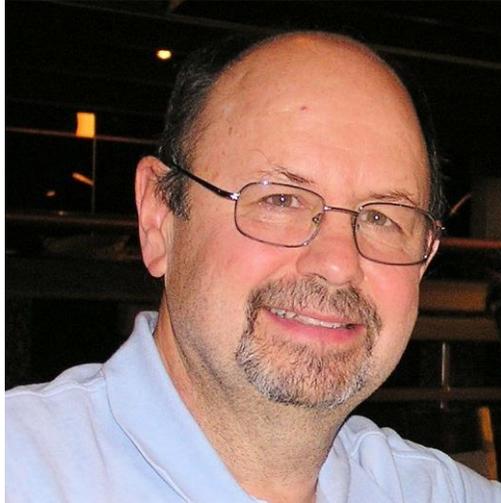
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## DEDICATION

To remember Randolph Martin Studier. To acknowledge that he lived, that he mattered, and that he was loved.





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## ACKNOWLEDGMENTS

To our sons, Christopher, Jason, Joshua and Chad, who loved their dad with all of their hearts. You guys were his best friends.

A special acknowledgement to Chad, who took on the colossal task of Caregiver for his dying father. I appreciate how difficult that was for you.

My thanks to the Northwest Wisconsin ALS Support Group; its leader, Deb Erickson; and its faithful members who traveled this road before and with us.

My heartfelt appreciation for St. Joseph Hospital's Hospice Team, who tenderly and lovingly cared for Randy the last few months of his life.

To our family and friends who selflessly helped us and showed Randy that he was loved.

Most of all I acknowledge God, our Father, for His sufficient grace, and our Lord Jesus Christ for the gift of salvation.

May you always find His grace sufficient.



## 1 SEASONS OF LIFE

*There is a time for everything, and a season for every activity under the heavens.  
~Ecclesiastes 3:1~*

“My name is Randolph Martin Studier, but I have been known as Randy, Marty, Mouse, Rass, Cheech, Dolph and Walrus.”

That is how my 61-year-old husband began his interview for a position with the University of Wisconsin Continuing Education Department.

“Although I am from Minnesota,” he continued, “I have ties to Wisconsin. First, two of my sons and their families live in Wisconsin. Second, the first professional football team I became a fan of was the Packers. Third, I like Leinenkugel beer.”

Randy paused and grinned at the hiring panel. “My daughter-in-law, Holly, reviewed this presentation. She told me that I had the order of those topics wrong; that in Wisconsin, it is beer first, then Packers, then family.”

He got a laugh and was offered the job.

It was September of 2009, and the University position heralded a season of new hope for Randy and me. This offer came after a time of frustrating employment for both of us. Randy, who held an MBA, had been laid off from two good jobs due to position elimination. Fearing he would never be offered another professional job at his age, he had resorted to working at Home Depot, which paid little and required exhausting work hours, not to mention having to wear the signature orange apron.

As for me, I had left my position as a family law paralegal and was unemployed.

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Randy and I owned a large house in Stewartville, Minnesota, but Randy's Home Depot income would not cover the mortgage and other household expenses. One of us needed to earn more money, and the job at UWEC came at the right time.

Randy began his new job in October, 2009. Our plan was for him to live in a small apartment in Eau Claire during the week while I packed up and sold the Stewartville house. Randy was enthusiastic about the new job; his co-workers were as friendly as could be. He looked forward to the cultural offerings of the college, especially the concerts. He planned on having several satisfying years at UWEC before retirement.

But shortly after starting the new job he went deer hunting, and he stumbled and fell. Multiple times. He came home and said, "Sue, I need help."

We soon learned that this season of new hope would be short-lived, and that we would enter the winter of our days together much earlier than we had ever anticipated.

## 2 SYMPTOMS AND DIAGNOSIS

*Our greatest glory is not in never falling, but in rising every time we fall. ~Confucius~*

Randy told me that when he fell to the ground in the woods he found himself unable to maneuver his feet into a supportive position. His legs and feet did not seem to work normally. With great effort, he managed to use his deer hunting rifle to pull himself up. He did not understand what was happening, but he realized that he had a serious problem.

Once home, he called his primary-care physician and obtained an appointment. The doctor ordered half a dozen blood tests, and referred Randy to a neurologist.

The neurological exam took place on November 11, 2009. I watched as the physician tapped Randy's knee with a small hammer. Randy's leg flew almost straight out. The doctor asked him to walk on his toes and then on his heels. Randy was unable to walk on his heels. The doctor said that Randy's reflexes were abnormal and that an MRI of the cervical spine should be done.

A few days after the initial neurologic exam, Randy had the MRI of his neck. No problem was found. The neurologist then ordered an MRI of the lumbar spine. Again, no explanation for Randy's symptoms was found. And so, an MRI of the thoracic spine was ordered and scheduled for November 30<sup>th</sup>, which was twenty days from Randy's initial plea for help, and sixteen days after the first MRI. We wondered why a single MRI of the entire spine was not suggested and performed to begin with. The waiting between tests was unbearable, given the potential diagnoses.

Randy feared he had a brain tumor, or a tumor on his spine from the prostate cancer treatment he had undergone just a year earlier, or worst of all, that it could be amyotrophic lateral sclerosis (ALS, also known as Lou

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Gehrig's disease).

Another reason we thought one single MRI should have been done is because of the cost. Each MRI cost around \$2,000.00. Surely, it would have been more cost-effective to do all three at one time.

While we waited for the next testing date, we went to our oldest son, Chris's, house for Thanksgiving with our four sons, their spouses, and our grandchildren. The guys tossed around a football, and Randy fell. Fearing he would not be walking much longer, Randy asked Chris if he would take him to see Chris's acreage north of Two Harbors, Minnesota.

Within a few days, Randy, Chris, and one of Chris's friends drove up north. Randy insisted on walking into the property to the beautiful huge pond. The land was heavily overgrown with large and small trees and thick brush. The guys walked up and down hills, over small creeks and on soft ground where it was wet underneath. They had to climb over fallen trees, duck through brush, and go around impassable areas. There were no trails and it was difficult even for a healthy person to navigate. It was about 500 yards to the pond, and it took almost 3 hours to get there. Randy fell many times, and Chris and his friend had to lift him back up on his feet. But once his goal was reached, Randy posed for a picture of his success.



*Randy, November 2009, victorious at reaching the pond on Christopher's acreage north of Two Harbors. Randy bought the M&M's before they went in and emptied the bag by the time they got out.*

## HEADING HOME

After Randy's northern Minnesota excursion we learned the result of the third MRI: The thoracic spinal cord was unremarkable. That was good news, but yet there was something drastically wrong and we were still in the dark: the fearful dark of unknown possibilities.

Randy went alone to see the neurologist on December 4, 2009. Afterward, he told me that he had asked whether his symptoms could be connected to the statin drug he had been taking since he had suffered a mild heart attack several years prior, or could the prostate cancer he had in 2008 have spread, or could it be side-effects of the drugs he took for the cancer. He asked whether he could have a brain tumor, or a virus that caused the symptoms. Desperate, Randy even asked whether a small boil he had on the back of his neck could cause the problems. The doctor told him that all of those possibilities could be ruled out.

After Randy told me all of that, he grinned at me. He said, "The doctor said that my symptoms could be caused by having sex with a woman from a tropical country."

"Really," I replied, "I think you'd better hope that isn't it."

"Well," Randy said, laughing, "it's either that or a bunch of jumbled nerves and veins called a spinal cord arteriovenous malformation. The doctor is referring me to Mayo Clinic in Rochester for that testing."

"When will they do it?" I asked, worried that it would be weeks away - weeks of more anxious waiting.

"I don't know yet, but I told the doctor that it was tough waiting between the tests, so he said he would request an expedited review of my symptoms so I can get in quicker."

While we waited for the Rochester appointment, we began to remember subtle symptoms over the last few months, which were insignificant in themselves, but which we now realized must have been the beginnings of whatever was wrong with Randy.

Prior to moving to Wisconsin, Randy and I had enjoyed bicycling around our town of Stewartville, Minnesota. Our favored route took 45 minutes and provided good exercise. I teased Randy that he looked like the Wicked Witch of the West on his bike. He sat ramrod straight and pedaled at a steady rate no matter if he were going uphill or down.

Each time we headed out, we would ride together for several blocks until we reached a stop sign at a main road. Randy never stopped for stop signs. I always obeyed and stopped. Thus, he was soon ahead of me. I asked him only one time to wait up for me. His method of waiting for me was to ride circles in the street, and as I approached, I saw him hit the curb and fly headfirst over the handlebars. I never asked him to wait for me again.

Usually, I managed to catch up to him at our turning point at the end of the path that snaked through the woods. He would stop for a rest and a drink of water until I joined him. From there, we would ride together until

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we reached the highway, where he would again ignore the stop sign. While I made a proper stop, alighting from my bike and carefully checking for fast-moving traffic, Randy used that opportunity to race to reach home first, where our neighbors chuckled at his competitiveness.

On our last ride in Stewartville, I headed out from the turn-around in the woods first and, several blocks later, became aware that Randy was nowhere in sight. I rode around a block twice, three times, watching and waiting. After the third round, I continued on our normal route and finally spied Randy across the football field riding slowly past the high school and taking a shortcut home. Though the bike ride that day was out of the ordinary, I gave it no further thought.

Hindsight also brought to mind that Randy had noticed an odd sensation in his shins in the mornings when walking down stairs. Again, at the time, it had been something to comment on, but nothing that caused undue worry. After all, he spent hours on his feet every day, which could explain those sensations.

The third clue we remembered was a walk we had taken that early fall with our adult son, Chad. Within three blocks of home, Randy was lagging behind. The next time I looked back, I saw that he had turned around and headed home. Chad and I completed our walk and, arriving back home, I asked Randy why he hadn't stayed with us. He claimed that we had walked too fast. I didn't think we had walked too fast, so I thought that Randy was simply tired from his Home Depot work hours, which had him rising at 3:00 a.m.

Randy got in for the testing at the Mayo Clinic in Rochester, Minnesota, on December 17, 2009. They checked his cerebrospinal fluid for cancer cells and performed an MRV of the spine to see if Randy had a jumble of veins causing the symptoms. The Mayo Clinic ran additional blood tests, double checking for Lyme disease, and including the test for the disease you can get from sexual relations with a woman of the tropics. The results of all tests were normal.

However, now Randy could not walk on either his heels or his toes, whereas a month earlier he had been able to walk on his toes. Additionally, he had fallen several more times since his early-November hunting trip, and when he walked, his feet slapped the ground in an odd manner, which we later learned was called foot drop.

As the Mayo Clinic tests came back negative, the list of possibilities shrank, leaving the most dreadful of them all: amyotrophic lateral sclerosis.

On January 25, 2010, the neurologist performed electromyography; a test that Randy and he had earlier discussed doing, but had put off, believing that it was unlikely to reveal much. By the day of the EMG, Randy had educated himself about the test such that he recognized the significance of the numbers the neurologist called out to his assistant. When Randy

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arrived home, he told me that he knew it was ALS.

His official diagnosis came three days later when we met together with the neurologist. It was January 28, 2010; a date that we would never forget. It was the date of Randy's death sentence.

### 3 LIVE AS IF YOU'RE DYING

*"I would make a good candidate for a suicide bomber about now." ~Randy Studier~*

What do you do when you are told this: You have ALS. There is nothing that can be done other than to treat the problems that will occur. When you can no longer walk, we will get you a wheelchair. When you can no longer swallow, we can give you a feeding tube. When you can no longer breathe, we can put you on a ventilator.

Not "if", but "when."

"Over the next two or three years," the neurologist explained on the day of diagnosis, "all of your limbs will be affected. However, there is a medication that may slow the progression of the disease."

"That's Riluzole, correct?" Randy asked. "I read about that. I found information that said it may or may not help some patients, and that it may extend a patient's life by 90 days." Randy glanced at me, a sardonic smile on his lips.

Turning back to the doctor, he said, "I must ask which 90 days might the drug extend? If it's the last 90, I don't think I would want that."

The doctor nodded, prescribed a walking cane and AFO braces (pictured below), and sent us on our way.



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Yes, he sent us on our way, but where do you go from an appointment like that? If the diagnosis had been cancer, we would have been proactively setting up surgery, chemotherapy and/or radiation. We would have had a plan. We would have had *hope*. Instead, we had this: sorry, but you are going to lose all ability to live, and you will die.

We had no plan. We had nothing that we could *do*.

Driving home from the clinic, Randy expressed his initial thoughts. First, he said, "I don't want to put you through this."

Then, he said, "I would make a good candidate for a suicide bomber about now."

We went home and over the next weeks we snuggled and cuddled and clung to each other. I would find Randy sitting in a recliner, his iPod in his hand, a blanket over his head, quivering with sobs. Or, lying across the bed, again silently sobbing and shaking. I would remove his shoes, rub his back, and hold him tight. There was nothing else I could *do*.

Aware that his life would be shortened, Randy decided he wanted to go on an ocean cruise with our four sons and their spouses. Randy and I had gone on several cruises in the past. Outside of hunting and fishing, it was the only type of vacation Randy enjoyed. Our son, Josh, immediately made the arrangements, and we were off to the Caribbean.

At the airport, even with the AFO braces and the cane, Randy's foot swung too far forward on the escalator and he almost fell backward. Then, right off the escalator, he nearly tripped over a piece of luggage that a small boy was pulling. Several other times, he stumbled over his own cane. Obviously, his leg muscles and feet were not working properly.

Though he was frustrated from those near-falls, Randy was determined to remain independent, and when we picked up our luggage at the Miami airport, he insisted on handling his own large suitcase. Then, when I headed toward the elevators next to the baggage claim, he said, "No. Take the escalators." And he headed toward them.

"Randy," I pleaded, "that's silly. The elevators are right here!"

But my husband could be a stubborn man, and so he had to prove that he could yet manage escalators.

When we boarded the shuttle van that would take us to our hotel, it took several attempts before Randy lifted his leg high enough to step into the vehicle. When he managed to get his foot on the floor of the van, however, he did not have the strength to push off and lift himself into the vehicle. My sons and I had to help.

The next morning, my family gathered for the shuttle that would take us to the ship. After checking out at the hotel's front desk, I turned to find Randy missing from the lobby. I went outside and found him sitting in the van, all alone, all buckled in.

"How did you do that?" I asked, "How did you get in yourself?"

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“I pulled myself up with the door. So, there.” He smirked.

I rolled my eyes, got in and sat beside him.

“I think I am going to cancel my trip to San Diego,” he said. He was scheduled to go to San Diego for work training in a couple of weeks. After the near-falls I had seen in the past 24 hours, I agreed that cancelling the trip was a good idea. He clearly needed assistance to travel.

Randy was exhausted by the time we boarded the ship. We found our room and then reported to the mandatory lifeboat drill. We were relieved to find our muster station had lounge chairs and tables, so we could sit. The staff announced that anyone who couldn't climb stairs should stay back when they lead us out, and they will put the names on a special assistance list. I asked Randy if he wanted to do that and he said no.

When the drill instructions were finished, we were told to line up in two rows, single file. Randy and I walked side by side to the steps that led upward. Randy stopped and said, “Oh, no. Steps.”

Immediately, we were asked to step out of line and report to the desk on level E to add our names to the special assistance list. The staff there told us that in the event of an emergency, we were to stay in our cabin and they would come to assist us. That was the first time I believed Randy was truly handicapped.

On the way back to our cabin, Randy said, “So, Sue, do you think they have any intention of coming to get us in an emergency?”

Before I could answer, he laughed and shook his head. “No, my Little Gumdrop, we are going down with the ship.”



*L-R: Chad, Chris, Randy, Sue, Jason, Holly, Josh, Brooke.*

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*L-R: Jason, Chad, Randy, Joshua, Christopher on the cruise ship*



*Randy and Chad on the Carnival Sensation, February 2010. This was Randy's first outing with a walking cane and the AFO braces.*

Susan Studier



*Randy and Sue at dinner on the ship*



*Randy and I stayed on the ship during shore excursions as it was too tiring for him to walk. He spent the time listening to music on his iPod and working crossword puzzles.*

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*Our formal portrait. Top L-R: Chad, Joshua, Holly, Jason, Randy. Bottom L-R: Chris, Brooke, Sue (Chris's wife, Janine, was unable to join us on this trip).*

## 4 FINDING SUPPORT

*"ALS is the worst disease on earth. I can't help but wonder how God can even allow it."  
~Jeannie Sunnarborg~*

**B**ack home in mid-February, Randy continued his research on amyotrophic lateral sclerosis and found a local support group that met monthly. On the way to our first meeting, I felt apprehensive at walking into a room full of people who were dying. How dreadfully morbid it would be. Besides, I still held hope that Randy did not truly have ALS; that his symptoms were caused by the leuprolide he had been taking for prostate cancer, or by some other obscure cause. Because of that belief, I entered the meeting room feeling that we certainly didn't belong in that group.

We were warmly greeted by the group leader, Deb Erickson, who had previously met with us at our home. She introduced us to the others, all friendly people, who wanted to know about Randy.

Randy told a little about himself and said that he liked to use his mind, so he would at least be able to keep on playing Fantasy Football, if nothing else.

I observed Stan Peterson and Jack Maypark, both with advanced ALS, in fancy big wheelchairs with gadgets that enabled them to read and use a phone, even though they could no longer use their hands. I was reassured to see that Stan and Jack were more functional than I had anticipated. Stan asked Randy questions about his diagnosis and condition, and Jack had the most appealing smile all throughout the meeting. I found myself relaxing with the group.

But then Deb served cake, and Stan's and Jack's limitations became fully visible: they could not feed themselves. Stan's daughter, Ivy, and Jack's wife, Bonna, stood beside each man and spoon-fed him. I believe

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that was the moment that I understood what this disease meant for me: I would be a “Caregiver,” a role that I knew would be difficult, demanding, and exhausting. I feared that I would not do a good job at caregiving; that I would not be as patient or as sympathetic as Randy deserved. Years earlier I had made a conscious, deliberate choice to not go into the nursing profession, knowing that it was not my calling.

Stan talked about his special phone and how it was set up with ten numbers programmed in it; a list of the numbers of the people who would quickly come to his aid, if needed. Stan explained how it worked without the use of his hands or arms. He said that the first number on the list would ring. If no one answered, then the next listed number would be dialed. Stan said, “So, whenever someone finally answers, I can say, ‘I’ve fallen and can’t get up. Bring the shotgun.’” As soon as I heard Stan say that, I knew that he and Randy shared the same sense of humor and would become friends.

The problem with being friends was that neither could drive, so it was difficult to get together. Randy managed to go visit Stan only one time, a visit that lasted about five hours. But they continued to see each other at a few more support group meetings, until Stan died that fall.

Jack, however, lived within blocks of our home and would ride over to visit in his wheelchair, accompanied by his service dog, Credo. Jack is the support group’s guide and inspiration. As of this writing, he is in his 11<sup>th</sup> year of living with ALS.



*L-R: Randy, Stan, Ole (Ole lost his wife to ALS in 2009), and Jack at the 2010 NW Wisconsin ALS Support Group Walk at Irvine Park, Chippewa Falls.*

## Susan Studier

The ALS support group became an important part of Randy's life. Not only did it provide a forum for speaking openly about his disease, but it also provided the tools and equipment Randy needed for his deteriorating physical condition.

Deb Erickson frequently stopped in to see us. Her initial visit was memorable. She gently questioned Randy about how he was feeling.

Randy blurted, "Why me?"

"Why not you?" Deb said.

Somehow, Randy appreciated and accepted that response.

At each visit, Deb determined which adaptive equipment Randy needed and then obtained it and had it delivered to our home. She was a guardian angel to us, especially since we did not know of the tools that were available to assist us with Randy's weakening muscles.

Most of the equipment was provided at no charge from ALS loan closets, and if we needed to purchase something, grants were available.

Another support group that Randy found was online at [www.alsforums.com](http://www.alsforums.com). His initial posting on the forum was in February of 2010:

*Hello Friends,*

*I was diagnosed with ALS January 28, 2010. I suspect that my initial reaction is not that uncommon....make it go away! And I'm still not accepting the situation.*

*In my heart I suspect that something caused the onset of my ALS. After all, motor neurons are basic to even the simplest animal life and should be pretty stable.*

*Is there anyone systematically collecting data about ALS onset and exposure to specific drugs, pesticides, chemicals, or whatever? I've read a lot of suspected causes, but am unaware if any substantial, collective analysis is being done.*

*I had initial exposure to four drugs for treatment of advanced prostate cancer with timing that seems to correlate to my earliest recollection of ALS symptoms: Eligard (6 month Leuprolide shot - relatively new to the market in this dosage), Bupropion, generic Cialis imported through Canada, and generic Levitra imported through Canada. I also had been on Simvastatin for at least six years. The MDs say these are not the cause of the problem. I've quit every drug except the Bupropion because it does wonders for depression.*

*Desperate because the clock is ticking and I'm barely walking!*

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A moderator on the forum responded with this:

*Sorry for your diagnosis, but welcome to the forum. In response to your post, this topic has been beat to death. There is no indication what causes ALS for any of us. Sorry but don't waste your energy trying to figure out what may have caused it. Take one day at a time and enjoy your life.*

Randy responded:

*Thanks for the responses and condolence! I'm sure the topic of cause has been beaten to death. I'm still hoping for some kind of escape. My wife and I are only beginning to understand what lies ahead.*

*My best to all afflicted and to caregivers,  
Randy*

The ALSforum not only provided Randy with the opportunity to share information and issues with other ALS patients, but also to create special friendships with people that he otherwise would never have connected. He gravitated to one lady who became influential in some of the most difficult decisions he had to make regarding his care.

Another website Randy liked was the ALS Functional Rating Scale. This provided sort of a symptom-checker where Randy would input his current symptoms and obtain a projection of the pace of his disease. It was through this exercise that he determined early on that his progression was more rapid than average.

Randy liked this website because of his analytical aptitude. When he spoke about it at a Support Group meeting, however, there was little interest in it from others. It reminded me of my mother who, when she had leukemia, never once asked what her prognosis was. She did not want to know. Thus, this website is not for everyone; but for those interested, it can be found by Googling “ALS Functional Rating Scale.”

Randy gained support from the sources noted above, but he also was compelled to offer support to the ALS cause himself. He accomplished that by soliciting donations from family and friends. They gave generously and, in 2010, Randy collected \$4,600.00 to donate to the local support group.

Many friends and relatives also attended fund-raising walks to support Randy, as shown in the photos following.

Susan Studier



*June 13, 2010 – ALS Support Group Walk & Wheel-a-Thon. 49 people were there to support Randy.*



*Our four sons, daughters-in-law, and grandchildren.*

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*Heading out for the 1 ½ mile walk. Granddaughter Ellie is carrying the banner. Our friend, Marv Bednar, is pushing the wheelchair. Dianna Bednar is on Randy's right. Obviously, she and Randy are laughing about something – there was always laughter with Marv and Dianna. They were frequent visitors during his illness.*

Randy's former boss, Mark Mueller, is behind Marv in the photo. He had this to say when Randy died:

*Dear Sue, Sons and family,*

*My deepest sympathies for such a great loss in your life. Randy was such an exceptional person and I know that I can't fully understand how much he will be missed in the family. I valued and appreciated Randy's friendship immensely. His intellect, humor and loyalty has been such an inspiration to me. The way he faced adversity in his last years with such courage, humor and humility is truly staggering and unbelievable. He is a bigger than life person to me. I feel so blessed to have known Randy and the Studier family. And, of course it goes without saying, it was wonderful to see that Randy got true religion when he moved to Wisconsin and became a Packer fan.*

Susan Studier



*June 12, 2011 – ALS Support Group Walk & Wheel-a-Thon.*



*Grandson Noab and Granddaughter Ellie carrying the banner.*

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*Randy at the finish line.*



*Randy and Josh at an ALS Walk in Janesville, WI. Josh's employer, Seneca Foods, generously donated to the event.*

Susan Studier



*Granddaughter Brittny led the Supersonic Studier team in Minneapolis in September 2010. With Randy in the photo are Chris, Janine, Elias, Sebastian and Annamarais. The banner was sewn by my sister, Linda Galkin.*

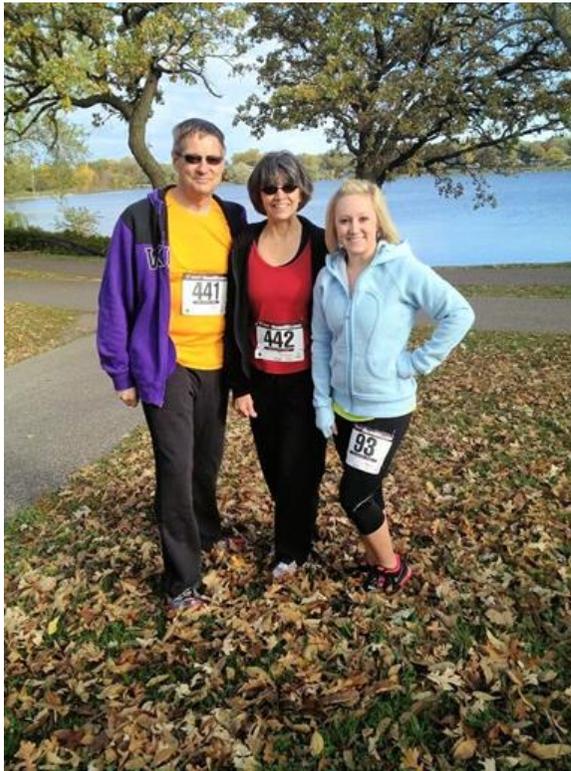


*Brittny ran the 5k in the 2012 ALS Superhero Dash in St. Paul, and took first place in her age group. She raised over \$1500 to donate to ALS. She cried when she won, and said, "I'll never stop fighting for Grandpa."*

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*Grandson Noah in the 2012 ALS Superhero Dash in St. Paul, Minnesota. He could have won first place in his group, but he was busy taking “selfies” while he ran.*



*Shari, Phil and Brittny ran in the 2013 ALS Superhero Dash in St. Paul, Minnesota. Brittny raised over \$2200 to donate to ALS.*

## 5 BREAK A LEG

*What is normal? Normal was yesterday. If you lose a leg, one day you're hopping around on one leg, so you know the difference. ~Terry Pratchett~*

**B**y March of 2010, Randy was falling from the slightest misstep. One day he fell when trying to get up from the couch and had to crawl across the floor to a sturdy dining room chair to pull himself up.

Another time, his foot brushed against a box in a hallway at work, and he went down backward.

He learned that he could not put his shoes on while standing on one leg. Even while holding on to a doorway, he fell backward more than once. Randy's nephew, Casey, loaned him a long shoe horn to assist with putting on shoes.



*Long-handled shoe horn.*

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In spite of the falls, Randy decided to go on the business trip to San Diego after a co-worker told him that he would help. I drove Randy to the shuttle pick-up. They had a step stool for him to get into the van. Even so, Randy could not lift his right leg up and into the van. I held back tears while asking his co-worker to keep a close eye out for such things. “He will be stubborn and he will say he can do it himself,” I warned the co-worker.

Randy was unable to enjoy the California city. He became exhausted from simply having to get up and move around the conference room throughout the day. He called me from the hotel and said he had skipped dinner because he didn’t know if he could walk the 2 or 3 blocks to the restaurant.

He expressed concern that the Director of the Continuing Education Department, who was at the conference, was seeing how deteriorated he was becoming. And he said that he did not want to work in a wheelchair, because he felt he would “not have credibility.” That was a negative thought that he would overcome. He ended up working from a wheelchair for many months.

After the trip, we noticed a new symptom common to ALS patients – fasciculation – which is persistent muscle twitching. We could see Randy’s muscles jumping, and I could feel it occurring when I lay beside him. The fasciculations were not painful. Randy said that it was like flashing Christmas tree lights throughout his body. He had the twitching all over except for his head.

It also became apparent that daily living activities now took a little longer for Randy: getting dressed, putting shoes on over the AFO braces, getting in and out of the car. He complained that rising from a chair was becoming difficult. His physical decline seemed frighteningly rapid.

I had secured a job at a law office located only 8 blocks from Randy’s office. Thus, because it was difficult for Randy to move around, I would make our lunches and go sit and eat in his office with him. The morning of March 24, 2010, I received an email from him: “Are you coming here for lunch?”

I emailed back: “Yep.”

His response: “Yipeel!”

That day, I went to his office at noon with homemade chicken noodle soup and turkey sandwiches. We sat in his office with the door closed and ate together. I looked at him and thought, “You are a good man; I can’t think of any time that you deliberately set out to hurt anyone. Ever. This shouldn’t be happening to you.”

Around this time, one of my sisters questioned whether his physical problems could be due to a vitamin deficiency. Randy responded:

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*No, I was tested for vitamin B12 deficiency. I wish it was something simple like that. I've been thinking about eating a very healthy diet again high in natural vitamins, but I'd probably just be eating crappy food as I'm dying!*

*I'm still walking, but it's tough getting through the day without tiring excessively. My blood pressure was 150/100 at the clinic after walking from the ramp to the Dr. office and my pulse was 108. My lungs and arms are affected and I'm not getting good sleep.*

*The Dr. reminded me that I'm dying, that I need medical power of attorney, and that I need to decide about feeding tube and ventilator support. He told me he has had a patient die in as little as two months after diagnosis with ALS. The visit was yesterday, and needless to say, a very depressing visit.*

Little did he know when he wrote that email that within two days he would never walk again.

On March 25, 2010, three of Randy's former co-workers from Minnesota, Sandy Voigt, Julie Vreeland, and Laurie Hennen, came to Eau Claire to take him out to dinner. After eating at the Olive Garden, Laurie was helping Randy up into the SUV, but Randy's leg failed to engage, he lost his balance, and they both fell to the ground. A Good Samaritan stopped to assist in getting Randy up on his feet and into the SUV. The ladies brought him home and helped him hobble into the apartment.

After a sleepless night, I took him to the clinic where they diagnosed a spiral fracture in his fibula. The doctor put him into an airboot and said she would order crutches.

"He can't use crutches," I said. I had seen enough falls to know that he would not be able to walk with crutches. She prescribed a wheelchair instead.

Now there was no normalcy in daily living: going to the bathroom alone; bathing independently; fixing his own breakfast; driving himself to work; all had become impossible for Randy.

## HEADING HOME



*Top, L-R: Sandy Voigt, Julie Vreeland  
Bottom: Laurie Hennen, Randy*

We went back to see the doctor that Randy spoke of in his email noted above. He was a physical therapy MD. We liked him. He was forthcoming and direct. He reminded us that we were on an unstoppable course.

Once he heard our situation - that we had recently moved to Eau Claire and were renting a small apartment - the doctor said, "Don't buy a house. Keep renting. The remodeling that you would have to do to a house isn't worth the short time that it will be needed."

He also told us that Randy needed to prepare a power of attorney and health care directive, which would direct Randy's wishes as to having a feeding tube and ventilator. He told us that if Randy wants a ventilator, he will have to be in a nursing home because Medicare does not pay for home care for that, nor are there many people trained to do home vent care. He informed us that he would be the doctor who would prescribe the

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personalized wheelchair and other equipment for Randy.

It was a relief to talk to this doctor. The last time we had met with the diagnosing neurologist, Randy asked if he would be managing Randy's treatment. The neurologist told us that he had done his part by diagnosing Randy, and that it might be good for Randy's young primary care doctor to manage his care, as it would be good for that young primary care doctor to "see what ALS looks like." The neurologist obviously did not understand that a person who has been diagnosed with a terminal illness would prefer to have a medical professional who was familiar with that terminal illness to manage his care.

Randy never gave up researching and learning about ALS. A few months before he died, we went to the specialized ALS Clinic in Hennepin County, Minnesota, where Randy impressed the neurologist with his articulate knowledge of the disease. Outside of the ALS specialists, it was obvious wherever we were that Randy had more understanding and knowledge of the disease than anyone else in the room.

Randy's research included alternative treatments for ALS, including acupuncture, special diets, Chinese herbs, stem cell therapy, and even having mercury-based tooth fillings removed. But his engineer-trained mind embraced the statistics, and he believed that any alternative treatment would merely keep him busy and not prevent the ultimate outcome.

Early on, he decided that he did not want to prolong a life where he could not be physically functional. He was horrified at one description of ALS: that you could end up being nothing more than a pair of eyes looking out of a body that could do nothing on its own. Thus, he decided from the start that he would not accept a feeding tube nor a ventilator, which can prolong life for a significant amount of time.

## 6 CAREGIVING

*It is one of the most beautiful compensations of this life that no man can sincerely try to help another without helping himself. ~Ralph Waldo Emerson~*

When Randy broke his leg, I was thrust into the role of caregiver. As mentioned earlier, it was a position that I felt apprehensive about. I had never considered myself a natural nurturer, like most of those called to the nursing profession.

I cringe when I read my journal notes (included in this chapter) from the early months of Randy's illness, but those were my feelings at the time. I resented the ALS diagnosis; I resented the prospect of losing my husband at a young age; and I resented the disease interfering with my life plans. I had not planned on this!

Our son, Chad, had recently returned from Washington to live closer to our family. Little did he know how close he would become. He also became Randy's caregiver, though he chose to not embarrass Randy or himself with the more intimate caregiving tasks. He and I called ourselves "Randy's A-Team."

A couple months after the diagnosis, my car started making a boing-boing sound underneath, so I parked it and planned to drive Randy's car the next morning to go to work early, wanting to make up missed work time for having to take Randy to the clinic with his broken leg.

On the morning of April 8, 2010, I turned the key in Randy's car and it wouldn't start. I got Chad out of bed to jumper cable it, but that didn't work, so he drove me to my place of employment. My journal entry for that day expresses how overwhelmed I felt:

*I just want to walk away from all these problems – the ALS, the broken leg, Chad's personal issues, cars that barely run anymore, being stuck in this tiny*

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*apartment til end of June. Went to ALS support group this afternoon. Topic – situational depression. They handed me a pamphlet entitled, “Caregivers Can Get Depressed Too!” Really. I’ve already been weepy for weeks. Caregiver. Who said I wanted that position? I would never have applied for it voluntarily. Then they handed us a pamphlet on feeding tubes!*

I did not express those feelings to anyone for fear I would be considered an unloving spouse. Later, when we visited the ALS Clinic in Hennepin County, we learned that some couples choose to maintain the husband-wife relationship and not become patient-caregiver. By the time I learned that, however, I was finding satisfaction in the caregiving role. But during those first months following the devastating diagnosis, it was, for me, a formidable expectation.

Much as I tried to suppress it, Randy discerned the stress I felt, and said, “We have to find a way to get you some free time. I worry about you sometimes more than I worry about myself.”

The free time for myself never happened. I wrote in my journal:

*April 24, 2010, Saturday – We have an unexpected free weekend and I am happy to have some time to choose what I will do. But it takes most of my time to do the laundry, shopping, cooking, vacuuming, washing dishes – we don’t have a dishwasher in this tiny apartment. At 8 p.m. the laundry is still not done and all I can think is that I am ready to “say Uncle.”*

One reason for my selfish frustration over our situation was that I had been working on writing a book about my grandparents, and had only recently been making good progress. Before moving to Eau Claire, I had stupidly worked long hours at my job, frequently 6 and even 7 days a week, which interfered with my writing time. Thus, I was excited when Randy secured his job at UWEC Continuing Education, because I planned to work only part time, which would allow me time to finish my writing project. But within weeks of having that dream, it was shattered by the ALS diagnosis, and I had to get a full time job because we did not know how long Randy would be able to work, and we needed health insurance. I had to tell my Rochester, Minnesota, writer’s critique group that I couldn’t participate anymore:

*Hi Helen, Anne, and Dave,*

*I remember a sermon in church when I was a young teen entitled, “If Only.” The preacher said that we should not obsess with thinking “if only” this had happened or “if only” that had not happened - instead, we should accept the Will of God.*

*But I can’t help it -*

## HEADING HOME

*My life would be extremely different, and I would have had something written for our next meeting:*

*If only Randy didn't have ALS;  
If only I hadn't had to spend several weekends cleaning out my Stewartville house;*

*If only I hadn't started a new, full-time job;  
If only people didn't come constantly to see Randy;  
If only Randy hadn't broken his leg and ended up in a wheelchair;  
If only I hadn't had to rearrange everything in this little apartment so that my son could move in with us to help with Randy. (We bought a house but don't get possession until the very end of June.)*

*Those are reasons why I have not written anything for weeks and weeks.*

*Instead, I have been spending those weeks taking care of my husband - taking him to Dr. visits; helping him bathe and dress; fixing his meals; taking him to the bathroom - day and night; taking him to work on the days that he feels good; leaving my office at noon and taking lunch at noon to eat with him in his office. During these weeks, I have realized more and more what a good man he is and always has been. I have been welcoming his old friends and his family and my family who love him and want to spend time with him. I have been patient with our sons, who want to be with their dad while they can. I have been patient with them even though they seem to think their dad and I are becoming incompetent in making decisions.*

*Hopefully, I will write again. Unfortunately, this month, I can't write and I can't read and critique. I just can't get into it.*

*Take care, everyone.*

From the beginning, Randy was grateful for everything I did for him; apparently he was thankful even when I did nothing for him, according to his email to me:

**From:** Studier, Randy  
**Sent:** Wednesday, June 02, 2010 8:29 AM  
**To:** Sue Studier  
**Subject:** Thanks for everything you do

*Thanks for letting me get my sleep last evening. I feel a lot better today.  
Love you,  
Randy*

Once he was in the wheelchair, many tasks fell solely to me. For instance, we were moving from house to house, and Randy was unable to lift the smallest box. Thus, all of that work was on my shoulders. Every

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weekend that we traveled from Eau Claire to Stewartville and back, I had to load up the car and unload it at the other end.

Another thing that changed early on was that Randy no longer could help with any household chores. He had always made his own breakfast, and frequently cooked dinner for the two of us. I will always miss his perfect stir-fried chicken, squash soup, and his version of potato soup that he perfected from my sister, Pat's, recipe. He had also cleaned bathrooms whenever company was coming. It goes without saying that I miss his assistance with that task; however, I would willingly clean ten dirty bathrooms every day if that is what it would take to have him still with me.

The scope of my caregiving increased as Randy's physical abilities decreased. At the same time, my trepidation at the caregiving role went away, and I gave myself over to doing the best I could for Randy.

Specific caregiving tasks are described as follows:

### Bathing

One of my first caregiving tasks was to help Randy bathe. I helped him transfer from his wheelchair to the shower chair (pictured below), I handed him the shower wand, the soap and a towel, and then helped him slide from the shower chair back to the wheelchair, using a slide board (pictured in the photo on next page). In addition to bathing purposes, we used the slide board to transfer between wheelchair and toilet, and wheelchair and recliner, and wheelchair and bed until Randy was no longer able to assist in his transfers.



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Once Randy was unable to assist with his own bathing, the ALS Support Group provided a large shower chair similar to that pictured below. We remodeled a bathroom to include a roll-in shower large enough to accommodate both the chair and the person who was bathing Randy. When I showered him, he loved to have me hold the shower wand over his head for a long time. He said that water pouring over him felt good.



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### Toileting

Three months after the ALS diagnosis, Randy said he could tell that his left leg was getting weaker and also his hands. Wheeling himself into the bathroom was tiring because his hands were becoming weak. He said I should buy a urinal bottle.

I said, “Are you serious?”

He shook his head yes.

So I went to the pharmacy and bought him a bottle to pee in. From that point on, I teased him that the perks of having ALS were that he got to sit around in his underwear and pee wherever he was. (Note in the photo below the blue bucket holding the urinal handy for him).



*Randy surrounded with the early adaptive tools: slideboard, long-handled reacher, urinal.*

When Randy’s shoulders, arms, and hands weakened, and he could no longer handle the urinal bottle, he started using condom catheters and disposable bags. If the catheter was not properly applied, we had leakage. If the bag was not properly closed, we had pee on the floor. Randy soon learned to ask the person assisting him to double check that the bag was properly closed.

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Another piece of adaptive equipment we used early on were grab bars on the toilet (pictured below, prior to remodeling the bathroom). In spite of the bars, Randy landed on the seat hard enough two times to break it. I shopped around to find a style of seat that stayed secure and added a raised seat to the toilet, and that solved that problem.



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And then came the day when Deb, the ALS Support Group leader, visited, and this conversation took place:

Randy said, “My hands are getting so weak that it is difficult to wipe myself.”

Deb, in her matter-of-fact manner, smiled and said, “Sue is going to have to pull on the rubber gloves and do the job for you.”

Oh, my. Never in a million years had I imagined doing that!

To delay that caregiving task, we bought a bidet, which allowed Randy to take care of himself in the bathroom for many months, but the time came when I had to get used to the rubber gloves and wet wipes.

The fear of having to go to the bathroom in public kept Randy close to home almost from the beginning. We did not know how we would handle it if he had to have a bowel movement when we were on the road. I couldn't take him into a restaurant Men's Room, and few facilities have a handicapped accessible Family Bathroom. Besides, time was usually of the essence in getting him onto the toilet, which was no easy task. At the June, 2011 ALS Walk, Randy had to be helped to the bathroom and physically lifted from his wheelchair onto the toilet. He emailed a friend about it:

*From: Randy Studier  
Sent: Jun 13, 2011 6:09 PM  
To: Dianna Bednar*

*[ALS] Walk exhausting for me...worst fear was realized, had to poop at park...four guys helped. Cousin Phil earned first CNA skill credit by wiping.*

Chapter 9 describes further bathroom issues.

### Dressing

Randy's feet swelled and he was prescribed compression stockings. The pharmacy measured Randy for the proper sized stockings; we paid \$45 for them, and then went home and struggled for days to pull them onto Randy's legs, putting a run in them right away. We were both sweaty by the time we were through. Randy finally mentioned to his occupational therapist that the stockings were nearly impossible to get on.

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The therapist said, “Didn’t the pharmacy give you the silk stockings and rubber gloves?” We did not know about those things. She called the pharmacy and requested the tools needed to help slide the stockings on easier.



*Randy's swollen feet.*



*The slippery fabrics and textured rubber gloves for pushing the stockings up.*

Randy's shoes would not go on over his puffy feet, so we purchased loose slippers. Usually, he wore heavy wool socks rather than shoes, as those were more comfortable.

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As mentioned earlier, Randy preferred to wear only a t-shirt and underwear. I objected to him going out for rides in his wheelchair around the neighborhood with only a blanket covering him, but he did that anyway. Jeans were difficult to put on him, so he gave those up and switched to wearing sweatpants on the occasions he needed to be dressed. When his hands became useless, and he could not help with dressing, I purchased tear-away pants, but the fabric was slippery and caused him to slide down in the wheelchair, so he did not like those. Thus, we did not bother with pants unless we had to go to a public event.

When my sister, Shari, found out that Randy hung around the house in his underwear, she gave him a pair of boxers that had a picture of a duck and the words “Butt Quack” across the back of them. Then, when Randy had home health care, I noticed that the CNA invariably had those boxers on him after every shower. One day I thought I would test her, so I placed those boxers on the very bottom of the pile of underwear in the drawer. Sure enough, she dug through all of the underwear to find those cute boxers.

Randy gained weight and eventually needed larger clothing. He asked that we shop at Goodwill or Savers, rather than spending more money at mall stores for clothing that he would not need for long.

### Grooming

I became Randy’s barber. Sometimes I didn’t notice how shaggy I let him get:



*I took this photo when I realized that I had neglected to shave him in a timely manner.*

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I also flossed and brushed his teeth (which involved holding a bucket while he spat), cleaned his ear wax, and dealt with boogers.

We had a two-day ordeal with a booger once. At the time, Randy could not lift his arms, so he asked me to retrieve the booger. I was not willing to put my bare finger in his nose, so I used Q-tips. But I couldn't get it. Randy told me I was pushing it up further into his nose and that I should stop. The next day, it was still bothering him, so he asked me to try again. He instructed me on the direction that I should manipulate the Q-tip, but, again, I was unsuccessful.

He then said, "Help me get my arm up."

Now, at that time, I couldn't simply lift his arm and hand right up to his nose - his muscles were atrophied - so I had to gently and slowly begin to move his arm up and down to loosen it, so to speak. Once his arm was malleable and in the right position, I had to guide his finger into his nose. He had just enough strength and movement remaining in that finger to capture the booger.

### Physical Therapy

I became Randy's physical therapist. Once the cast came off his broken leg, Randy had physical therapy to get him back on his feet. By that time, however, the ALS had worked its damage, and Randy no longer had the muscle strength to walk. On July 2, 2010, we saw the physical therapy MD. He told us that Randy's walking days were over and that he should not even try anymore. Thus, it was only 5 months after being diagnosed with ALS that Randy lost his ability to walk. The doctor prescribed a permanent handicapped parking permit and occupational therapy to teach us how to keep Randy as mobile as possible. He told Randy to stop the physical therapy that he had to get him walking again, and instead begin therapy more appropriate for ALS issues. I was taught how to manipulate and stretch Randy's limbs and hips to preserve his range of motion, and that became a nightly routine.

### Chauffeur

I became Randy's chauffer. Randy hated giving up driving. He drove a car longer than he should have. In hindsight, I am appalled that I rode in a vehicle that he was driving when he could not lift his leg from the accelerator to the brake. He would pick his leg up with his hand and move it over to the brake. That, of course, slowed his reflex time. Other ALS patients admitted that they had driven vehicles longer than they should have.

When we went to the Department of Motor Vehicles office in Eau

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Claire to apply for Wisconsin driver's licenses, Randy was in a wheelchair. Still, he asked for an application for a driver's license. When we were called to the counter, the agent asked, "Sir, why are you in a wheel chair?"

With a strong voice, Randy said, "I broke my leg." Then he mumbled, "And I have ALS."

The lady gazed at him for a moment and then said, "How long will you be in the cast?"

Randy replied, "For six more weeks."

The agent said, "You will have to take a behind-the-wheel test when you are out of your cast."

Defeated, Randy said, "Just give me an ID card, please."

So I became the driver. And Randy became the proverbial back-seat driver. It was not fun. Too many times he would shout for me to turn when it was too late for me to turn. Driving him around was a most stressful thing for both of us.

I drove him to work for several months during which time he used a manual wheelchair. I would wheel him from the house to the car, help him transfer into the passenger seat, fold the wheelchair and lift it into the back seat. Upon arrival at his office building, he wanted me to park very close to the curb without actually hitting the curb. Sometimes I hit the curb.

### Transferring

Transferring Randy from place to place became more difficult as the disease progressed. When he could no longer stand alone, we used a piece of equipment that we called a "sit-to-stand," similar to the photo below, to transfer him. I would wrap a gait belt around his waist, position his feet on the base and his hands on one of the top bars, then would pull him up with the belt so that his knees locked against the pads. Then, I would pivot the base so that he would be positioned to sit again. This worked well until his knees started buckling.



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Randy insisted we use the swivel longer than we should have. One evening I was alone with him and was transferring him from his wheelchair to the bed. I placed the gait belt around his waist and pulled him up, but his knees buckled, and he fell back into the chair. The second attempt was a failure also, but that time I noticed that his face was scrunched up in the goofiest expression I had ever seen on him (he was concentrating with all his might on trying to get his body to do what he wanted it to do). I doubled over with laughter, and he joined in. I didn't think we would ever get him transferred into bed that evening, but after we settled down, we made it on the third try.

Pictured below is the Hoyer Lift. A co-worker of mine, Beth Johnson, had this one available and loaned it to us. Randy resisted its use. I wanted to use it far earlier than he agreed to try it. His knees had been buckling, but thankfully, his falls to the floor occurred when other people were around to pick him up. If he had fallen when only I was there, he would have had to stay on the floor until outside help arrived. I would not have been able to pick him up by myself.

I understood Randy's resistance – the use of a Hoyer Lift meant acquiescence to his utter dependence on others for his every movement.



*Chad transferring Randy from wheelchair to bedroom with Hoyer Lift.*



*Poor Randy got clunked on the head with the top bar more than once when we lowered him onto the bed. Still, see how he smiles.*

Using a Hoyer Lift is a multiple-step process. A sense of urgency filled the room whenever Randy was in bed and needed to go to the bathroom. First, the Lift was retrieved from the other room. Then, the sling was folded in half and placed next to Randy's body. Third, Randy was rolled over to his side, which became increasingly difficult as his muscles failed and he could not assist in moving his body weight. The sling was then tucked in against his back, and he was rolled back. I would then walk around to the other side of the bed, roll Randy the other way, and tug the sling open underneath him. The Lift was positioned next to the bed, the sling straps attached, Randy was lifted and transferred across the hall to the bathroom. During the transfer, I would pull his underwear down so that all would be ready when we reached the toilet.

Positioning him on the toilet was challenging. For one thing, he had to be in the right spot for the bidet to properly cleanse his bottom. The other issue was that the fat on his butt was gone, so he was sitting with bone on porcelain, which was painful. It always took a series of small adjustments to help him avoid discomfort on the toilet.

If you would like to see how to operate a Hoyer Lift, you can find videos on [www.youtube.com](http://www.youtube.com).

### Feeding

As his hands weakened, Randy would lose hold of his fork or spoon and spill on himself, so my sister, Linda, sewed a bib for him (pictured below). We also obtained long straws, padded utensils, and an easy-to-hold cutting tool.

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I had dreaded the day that I would have to spoon-feed Randy. But when that time came, and the awkwardness faded, I found that caregiving task inexplicably self-satisfying. Perhaps that was due to the realization that Randy was now totally dependent on me (or another person) for his very survival. It was similar to nurturing a much-loved helpless infant. I called him my Baby Huey (after the old cartoon duck).

I suppose that our grandchildren thought it odd when Grandpa had to be spoon-fed, though the only one who commented on it was Paul. My journal entry dated August 1, 2011 was this:

*I became convinced that our 10-year-old grandson, Paul, has a solid grasp on what it means to have ALS when last night, as he watched me spoon-feed Randy, Paul asked, "Grandpa, does it suck to have ALS?"*

One weekend I had a houseful of grandkids, and I asked who would feed Grandpa Randy some watermelon. The only volunteer was four-year-old Gus.



*Four-year-old Gus feeding Randy watermelon.*

## Night Care

Caregiving does not stop once the sun goes down. Sleeping was a problem for Randy from the beginning. I noted my feelings about that in a journal entry:

*July 2, 2010: Four hours of errands, then cleaning and unpacking in the new house until 10 pm. My right shoulder is injured from overuse – I can feel it. I am exhausted after this week and can't wait to sleep in a bit tomorrow. We agree to leave for Sun Prairie at 9 or 9:30 in the morning, which will allow me to sleep until 8. Abhh, love those kind of Saturday mornings.*

*Randy dozes in his recliner, then wakes up and announces he is going to sleep in the bed. I help him get in – it's a high bed and he has to transfer from the wheelchair to the side of the bed then throw himself straight backward to get on it far enough. We get his legs up on the bed and then with great difficulty he tries to use his nearly useless legs to push himself into position up toward the headboard.*

*He wakes me twice during the night – once to help him go to the bathroom and another to shut the ceiling fan off. Then he wakes me before 6 a.m., just because he is awake. He doesn't need anything; he just throws his arm over me and massages my arm. "What time is it," I ask. "Almost 6," he says. "Then why are we awake!" I say. "Sorry," he says. But the damage is done and I am up for the day feeling exhausted and we have a long day ahead of us – a 3 hour road trip to watch Noah march in a parade and then a 7 p.m. field show of Noah's marching band. Then drive 3 hours home after that. Then, tomorrow and Monday, I will have a houseful of two families – Chris's and Josh's. And I still am not moved into the kitchen of the new house, much less the bedrooms and bathrooms.*

At one point, Randy was prescribed Ambien to help him sleep. Before bedtime on the first night he took the drug, we worked on a jigsaw puzzle that had turtles in it. In the middle of the night, he woke me up to get the urinal. At that time he slept in a hospital bed in the same room with me. I got out of bed, held the urinal for him, then went to the bathroom to empty it. The entire procedure took about 15 minutes. I fell back asleep, but was soon wakened by his thrashing about. I got out of bed again and asked him if he wanted to get out of bed and go to his recliner.

He said, "No, the fighting is not over."

"What fighting?" I asked.

"The turtles over there."

I looked in the direction he was looking. I didn't see any turtles. "What turtles?" I asked.

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“Shoot the turtles!” He said.

I watched him for a moment longer until he said, "Tell them, Sue!"

Then I went back to bed.

In the morning he remembered the dream. He also remembered feeling suicidal at one point during the night. He never took a sleep medication again.

Soon after that night, the ALS Support Group provided an air mattress for the hospital bed, which pumped air throughout the mattress all night long, alternating pressure points so that Randy would not develop pressure sores. That air mattress was one of the best pieces of adaptive equipment as far as Randy's comfort went, but we still had countless sleepless nights. On May 21, 2011, I wrote:

*Last night - to bed at 11:45 p.m. Up at 12:30 and 1:30 and 2:30 and 3:30 and 5:30 for adjustments to make Randy comfortable. Hope tonight will be better.*

And on July 8, 2011, I wrote:

*Wondering how many days I can go without sleep before yanking my hair out? It has been 4 nights now.*

And my note of July 16, 2011:

*Randy had me up 7 times last night trying to get him comfortable. So is it any wonder that I would make a Freudian slip this morning when I asked him if he wanted a head under his pillow?*

By mid-September, 2011, Randy was on a regimen of Advil, Lorazepam, Seroquel, Miralax, Colace, Morphine, and a Fentanyl patch. I kept a log of meds because I was so exhausted and would not remember when I had last given him a dose of something. My log of the evening of October 5, 2011, and the early hours of October 6, 2011, was this:

10:00 p.m. Loraz (3), Morphine, Ducolace, Advil

10:25 p.m. Get another blanket

10:40 p.m. Get another blanket

12:00 a.m. Straighten his head; massage his neck; switch pillows around

12:30 a.m. Morphine, check BiPAP mask, roll him over, readjust pillows

2:40 a.m. Get him drink of water, roll him over, readjust pillows

4:00 a.m. Morphine

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5:00 a.m. Nose itches; get wet rag and rub his nose, roll him over  
5:10 a.m. Chest itches; scratch his chest; feet hurt; massage them;  
remove one blanket  
5:50 a.m. Take him to bathroom  
7:45 a.m. Lorazepam (3); morphine

As the ALS progressed throughout Randy's body, he lost muscle, and was becoming skin and bones. This caused him much discomfort, especially with his sacrum. His sacrum hurt when he sat; it hurt when he lay in bed; it hurt when we put him on the toilet.

At night we tucked him in on his back, but he needed to be rolled from back to side to other side at least every two hours; not only to prevent pressure sores, but also to relieve sacrum discomfort. I am short-statured, and even with the hospital bed at its lowest position, it was difficult for me to get him rolled over. If he was on his back in the center of the bed and I rolled him to his side, he would end up with his face against the side rails. Thus, I had to tug on the sheets to position him close to one side of the bed before rolling him. Then, after he was repositioned, it took more sheet-tugging to get him comfortable as the slightest wrinkle in the sheets bothered him. We eventually obtained a large piece of sheepskin to put under the sheet, and that helped.

Another problem was that he liked the head of the hospital bed elevated a bit, which caused him to slide down toward the bottom of the bed. So, every time I got up to tend to him, I stood at the head of the bed and pulled on the bottom sheet to reposition him. At first, I put my hands under his armpits and pulled him up, but I learned that it was easier to pull up on the sheet instead.

Randy usually needed 9 pillows to be comfortable in bed. The first pillow went under his calves, such that his heels would not touch the bed, as that bothered him. Then two pillows were placed between the soles of his feet and the end of the bed; otherwise, his feet dropped downward and caused discomfort. Two pillows went between the bed rails and his face, using fat, soft ones against his cheeks. And two pillows went under his head. Many nights, we repositioned pillows over and over again in order to have all nine perfectly arranged for his comfort.

By June of 2011, Randy was using a BiPAP machine. A BiPAP is a breathing assistive device (pictured below). At first, he used it only at night when sleeping, but gradually increased the usage to around the clock.

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The BiPAP uses water. The first night Randy used it, he woke me because the mask was full of water. We called a technician to figure out what the problem was, and he told us that the tubing had to be up over Randy's head, rather than straight over from table to bed.

Positioning the mask on Randy's face was usually a challenge and took several adjustments until he felt comfortable. After time, he developed sores around the bridge of his nose, and we had to pad those areas with gauze.

It took a full hour for Chad and I together to tuck Randy into bed.

### Scratching

Finally, a caregiving task that is unique to those caring for people who cannot use their hands, is scratching. The worst tale I heard from an ALS patient was when Stan told of being outside on a nice summer day on the farm. The family helped him get outdoors and then left to run errands. Stan, alone in his wheelchair, was soon attacked by both mosquitoes and biting flies. Unable to raise his arms to swat them away, he wheeled himself to the clothesline and desperately tried to rub his face on the pole. He said that it was pure torture.

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Randy did not like using bug spray; he disliked the lingering scent of it. Gnats in the yard were a problem for him. I could not brush them away fast enough to keep them from pestering him. Thus, he seldom ventured into the yard when they were around. The gnats were particularly bothersome in September of 2011, on the day we had our final family photo with Randy taken professionally. I hovered over Randy, frantically swatting at the gnats, until my family had sprayed themselves sufficiently to repel the bugs away from our entire group.

One day when I was tending to Randy as he lay in bed, he asked me to scratch his armpit. I lifted his arm, looked at that dark, damp, hairy pit, held my breath, and scratched. The next day I thanked the home health aide when she told me that a dry washcloth works well for that.

The last couple months of his life, Randy's head itched. I would anoint his bald scalp with baby oil and use the brush pictured below to scratch his head. That felt good to him.



Randy was a man. Men itch. I had to scratch. Enough said.

Caregiving was overwhelmingly exhausting, but at the same time, wondrously fulfilling. It was a unique experience, one of utmost value not only to Randy, but also to myself. When Randy's sister, Jill, asked who takes care of me, I responded:

*My position on "who takes care of Sue" is that this is not about me; it is about Randy and his comfort and letting him know that he mattered and was loved. Sue will fall apart later and might need some caregiving herself then :).*

One day Randy asked me, in reference to our wedding vows, "Sue, do you think this is the `for worse' part?"

I said, "No."

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Even though I had to tend to him as you do a small child, and even though I was responsible for all household chores by myself, and was working full-time on top of it all, I knew that the "for worse" part would come when I would be without him.

I did my best for Randy, but there were a couple of times when exhaustion and frustration overtook me and I made a snarly remark. Once, after a particularly lengthy readjustment period trying in vain to make him comfortable in bed, I said, "You know, if I was the one with ALS, I would be in a nursing home."

He cried, and so did I. I don't think I have ever felt as horrible about myself as I did then. My profuse apology included many kisses and hugs.

I always felt better when other people were around. One day following a weekend visit from my siblings, I stood in the kitchen feeling lonely and anxious. I missed my siblings, and I missed my friends, Tami and Helen. I whispered to myself, "Who is going to help me get through this?" I immediately heard in my mind, "I will." Recognizing that as from God, I opened my Bible and found 2 Corinthians 12:9. I printed it out and hung it on the bedroom wall:

*<sup>9</sup>But he said to me, "My grace is sufficient for you, for my power is made perfect in weakness." Therefore I will boast all the more gladly about my weaknesses, so that Christ's power may rest on me.*

That verse sustained me throughout Randy's illness, and still does to this day.

## 7 ADAPTING TO ALS

*When you can't change the direction of the wind – adjust your sails. ~H. Jackson  
Brown, Jr.~*

According to the ALS Association website, there are “medically documented cases of ALS that ‘burns out,’ stops progressing or progresses at a very slow rate.” Those cases are the exceptions. Generally, once you have ALS, you are on a non-stoppable course of physical deterioration. At the time Randy was diagnosed, we could look back two months and see the changes. As the disease progressed, the changes were more rapidly noticeable.

By June of 2010, Randy’s leg fracture had healed, but his legs were weakened and he struggled to walk. He tried to use a walker, but frequently tripped over his own feet from foot drop syndrome. Because Randy’s ALS first presented in his feet, those muscles were first to weaken such that he could not properly pick up the front part of his feet. It was the foot drop that caused Randy’s numerous falls. Thus, he continued to use the wheelchair for most of his mobility.

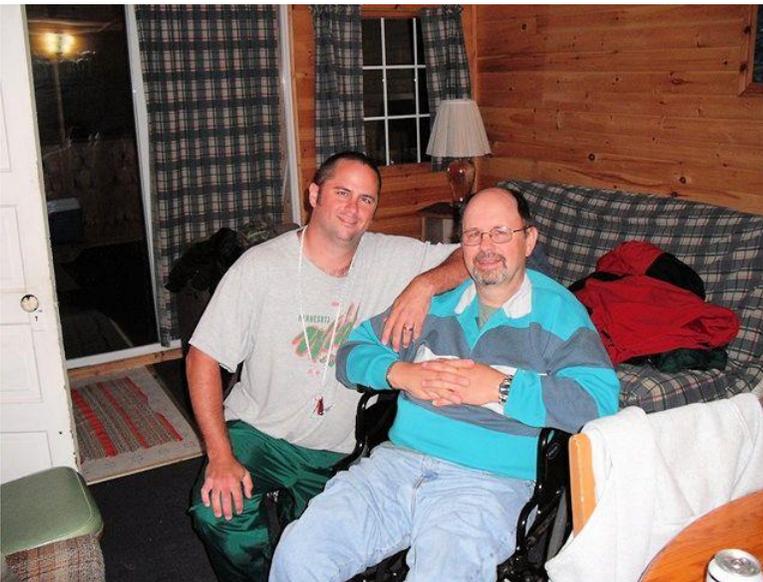
In spite of his deteriorating condition, Randy wanted to go on the annual spring fishing trip with our four sons and his best friend, Jim Sunnarborg. Throughout his adult life, Randy spent nearly all of his work vacation time on camping and fishing outings in Northern Minnesota. When our boys were little, I went along and endured the primitive outdoor conditions. When our boys were old enough to survive without their mother’s constant supervision, I sent them off to camp with their dad while I stayed home and learned to enjoy time alone.

On Randy’s final fishing trip, it took four of the guys to help him get out of the boat, and when he was out, his knees buckled. That was a new development. Later that day he thought he could descend the cabin steps himself, but he was intercepted by those who saw what he was doing, and that was a good thing because he almost fell. I still wonder what would make a man who had been in a wheelchair for two months with a broken leg *and* ALS think that he could walk down steps!

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*Randy and Jim Sunnarborg on their last fishing trip June 2010*



*Josh and Randy on the last fishing trip – June 2010*

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After that last fishing trip, we moved from the tiny apartment into a house. Contrary to the doctor's advice, we decided to buy a house in Eau Claire. At the time, we were hoping Randy would get at least the "five-year" survival window for ALS patients, rather than the shorter, three year window. Actually, the statistics at that time were that 50% of diagnosed ALS patients would die *within* 3 years; and 80% would be dead *within* 5 years. Still, I had heard "five years" and I was claiming that.

The home we purchased was based on two important criteria: it was within a price range that we could pay cash for so that I would not later be burdened with a mortgage, and it had potential for handicapped accessibility. It was a ranch-style house, with door access to both the main floor and the lower.

Randy and I were blessed to have contractors in both of our families. His sister, Jane's, husband, Ed Pecora, came all the way from New York to build the wheelchair ramp for Randy to get in and out of the house. Ed worked hard for days in the worst heat of the summer and all through a rainy day. Later, my brother, Kenny Schmidt, nephew, Mike Schmidt, and my sons, Chris, Jason, Josh and Chad, extended the ramp around the side and down behind the house to connect it to the walk-out basement. Thus, Randy could access both floors of the house, and also the backyard, where we had placed a fire pit for the campfires that Randy loved.



*L-R: Randy, Chris, Josh, Chad, Kenny, Mike and Jason beginning the ramp.*

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*When I look at this picture, I see Randy's helplessness. He was an exceptionally intelligent, talented man who could build, fix, and do anything he set his mind to do. He designed the ramp around the side of the house, but could not help build it.*



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*Chris came up with the idea to modify this ramp to add access to the yard. See next photo.*



*Now Randy could access the backyard and enjoy the fire pit.*

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*First trial run.*



*Rain or shine, he loved the fires.*

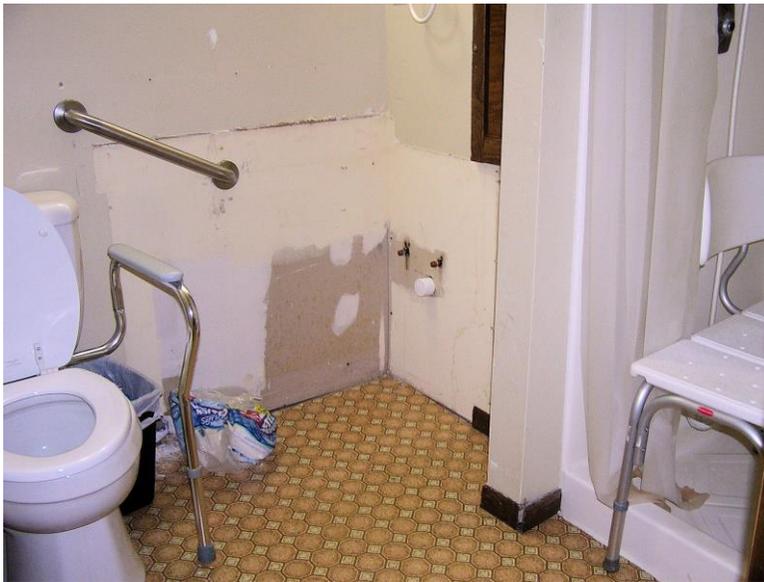


*Neither rain, nor snow, nor gloom of night kept Randy from a campfire - we enjoyed roasting hotdogs over a campfire on a clear, crisp January evening with my siblings.*

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After we solved the problem of accessing the house in a wheelchair, we addressed the bathroom situation. Many ALS families remodel a bathroom to accommodate a wheelchair. We had two bathrooms. The one on the main floor was large enough to accommodate the wheelchair, but not large enough to turn the chair around, so backing out was always a challenge. The lower level bathroom was so small that my brother, Kenny, removed the vanity and sink so that Randy could get in with the manual wheelchair.

Behind the back wall of the small bathroom was a large closet, which allowed us to remove the wall and build a large, roll-in shower. The plumber researched handicapped code and installed grab bars all around the shower and toilet. Those bars were of no use to Randy, however, as his hands were soon too weak to use them. Because of Randy's ALS, I learned that "handicapped accessibility" is actually a minimal accommodation for people in wheelchairs. Those with paralysis need much more adaptive equipment than ramps and grab bars.



*The vanity in this small bathroom was removed to make room for the wheelchair. Later, this bathroom was expanded as shown below.*



*A large closet behind the small bathroom allowed us to remove the back wall and have this large tiled roll-in shower built.*

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*As Randy's hands weakened, personal hygiene became difficult, so we installed a bidet on the toilet. The wall-hung sink allows wheelchair access.*

## 8 FAMILY

*A sick person needs “. . . the absence of pain and the presence of family.”*  
~Helen Hayes~

Once diagnosed with a terminal illness, Randy had a heightened desire to be close to family. Unfortunately, we had moved further away from his siblings, which made frequent visits difficult. I asked Randy several times whether he wanted to be close to where his brothers, Tim and Dan, lived; that we could move there and be near them. But he always said no. He was concerned for my future, and since I liked my Eau Claire job, he wanted to stay so that I could establish myself in the community, and have a life here after he was gone.

Our sons were scattered: Chris and his family lived 2 hours away; Jason and his family lived 2 hours and 45 minutes away; and Josh and his family lived 3 hours and 15 minutes away. They were all busy with the grandchildren’s activities, so we tried to go visit them. We soon found that getting in and out of their homes, without wheelchair access, was problematic. Also, some of the homes did not have bathroom doorways wide enough for the wheelchair to pass through. In one home, we had to remove the door so that Randy could get into the bathroom, which left him open to exposure.

We tried staying in handicapped hotel rooms a couple of times, but we needed help getting Randy onto the beds, and those nights were nearly sleepless from Randy’s physical discomfort. Thus, we found traveling more challenging than we liked, and preferred that people visit in our home.

After Randy broke his leg, Josh and Brooke and their three little boys came to visit. The boys scrutinized Randy’s wheelchair.

“Why can’t you walk, Grandpa?” Five-year-old Leo asked.

“An alligator bit off my legs,” Randy replied, “and after the doctors

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sewed them back on, they don't work anymore.”

Leo understood it was a joke, but I am not sure what 4-year-old Niko believed, as he simply said, “That’s okay, Grandpa, the wheels on the chair can be your legs.”

Another “out-of-the-mouths-of-babes” comment came from 6-year-old Ellie. When Randy telephoned her home, she answered and said, “Hi, Grandpa. I heard that you are going to die in five years.” Her matter of fact statement merely amused Randy.

During Randy’s illness, every time my siblings visited, they brought home-cooked foods and stocked my freezer. That made my life easier. One time, however, I thawed and heated the frozen goulash that my sister, Linda, had brought and served it to Randy and Chad. After a few bites, they both said that it was not good and that they couldn’t eat it. Neither of them were finicky eaters, so I tasted it. I had to agree. I threw it out. The next time Linda asked what she could bring, I gently said that Randy preferred my goulash recipe. That’s when she admitted that she knew hers did not taste good. When Randy found out that Linda knew her goulash was not very good and she gave it to him anyway, Linda’s faux pas became legendary.

People on both sides of our families contributed to our situation: Ed donated a week of his time and labor to build the front ramp. Randy’s brothers, Tim and Dan, assisted on that project. Angie and Jane cleaned, altered curtains, and arranged furniture after we moved into the new house. Angie generously purchased an outdoor slate table where Randy could sit and play cards; and Jane left a large check, which went to purchase the chairs to go with the table.

My brother, Kenny, and nephew, Mike, built the side ramp, with the assistance of our four sons. My sister and brother-in-law, Shari and Phil, spent a few days with us doing all sorts of indoor and outdoor chores. They purchased bird feeders and a bird bath and set them up where Randy could easily view them from the house. They also left a huge check to go towards the bathroom remodel expense. My sister and brother-in-law, Pat and Rick, waterproofed the ramp during the hottest days of summer, and also cleaned up the flower gardens and prepped the vegetable gardens. My sisters, Linda and Carol, and my niece, Christine, sealed the grout in the new bathroom, and cleaned for me.

All of our relatives were cheerful givers, and I can’t express how much we appreciated their time and assistance. Most importantly, they showed their love for Randy, which made him feel good. He told me that he liked it when his visitors cried because he felt loved when that happened.

As difficult as it was for some people to visit Randy and see his deterioration, it was important for Randy to be surrounded by people he loved. He wished that he had more time with his family.

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My brother, Kenny, a/k/a Butch, was Randy's go-to contractor throughout the years. Randy wanted to let Kenny know how he appreciated that, so he left this letter for him:

*Dear Butch,*

*I am so lucky to have you for my brother-in-law. You were always right there when I needed a job. You taught me so much about home construction. I remember how you helped us build our house in Chisholm and how you cared enough to drive way up there. You saved us a lot of money. I remember you helping me figure out how to fix the floor on that house. More recently, you helped with my ramp that gave me independence just a little while longer. As I said before, you have always been there. And I appreciated it. Just as important perhaps, is that you gave my boys the opportunity to learn the basics about carpentry. I can't thank you enough for sharing that craft.*

*We had many good fishing trips together. Our trip to Manitoba was especially memorable. I would have given anything to have gone on the trip with you last year, but, of course it was not to be. I won't soon forget the fun we had playing basketball and the hours and hours of cards.*

*Thanks again for being there when I needed you. I love you like a brother, Butch. Think of me when you catch the next big walleye. I wish you good health and hope that you go on to enjoy your kids and grandkids for many years to come.*

*Love,  
Randy*

Randy loved fishing and camping; he loved watching his boys play hockey; he loved the Yankees; he loved watching professional football and hockey; he loved going on ocean cruises. Yet, in January of 2011, when my sister, Linda, asked the guys in the family what their favorite thing in life was – sports or fishing or flying or going on cruises, etc., Randy's response was this:

*Spending time with Sue and the boys, especially watching them enjoy things.*

ALS reminded us that life is about the love we have for one another. Nothing else is as important as that.

## 9 SAYING GOODBYE

*I've been a Yankee fan for so long that I got Lou Gehrig's disease. ~Randy Studier~*

Randy started his job with the Continuing Education department of the University of Wisconsin Eau Claire in October of 2009. He was diagnosed with ALS three months later. Within five months, he was in a wheelchair. He continued to work until the end of August, 2010, at which time he was fatigued most of the time and nearly unable to transfer himself to the toilet at work. Fearful that he would one day end up falling on the floor of the office bathroom, he decided to retire.

On August 30, 2010, the Continuing Ed department held its summer picnic. At the end of the picnic, the director of Continuing Ed called for everyone's attention. He said that he had promised Randy that he would not embarrass him with a long speech. He said, "We are not going to say goodbye or good luck to Randy. We are just going to say, thank you. Thank you for giving us a year of your time. You have made us a better place."

I felt proud and happy for Randy that he ended his work-life on such a positive note.

Once retired, Randy brushed up on the game of bridge, which he hadn't played for years. Then, he had Chad wheel him to the nearest bus stop where he boarded a city bus, which was equipped to load wheelchairs, and went to the Senior Citizen Center to play. He went only a few times, though, because he found the excursion fatiguing, and the bathroom issue always loomed over him. He also arranged for door-to-door handicapped van service, but used that only a couple of times to get to appointments. Thus, though he had options to get out and about the city, he preferred to stay home.

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When professional football season began, he entertained himself by playing Fantasy Football. He had all the time in the world to research and study now, and his fantasy teams performed well in the league.

When professional baseball season started, Randy's sister, Jane, purchased a subscription to the Yankee website that allowed Randy to watch all of their games. Randy had been a Yankee fan since he was a little boy. In October, 2010, as Randy and I watched the Yankees play the Rangers, he turned to me and said, "I've been a Yankee fan for so long that I got Lou Gehrig's Disease." His delivery of that line was impeccable and hilarious.

As he reflected on his life, he wrote this:

*My first memory of baseball is watching the game of the week on TV in our large Glenville home. The game was always the New York Yankees and whomever they happened to be playing on the particular Saturday. Dizzy Dean was one of the announcers. He was a former major league pitcher who would always sing the Wabash Cannonball during the broadcast. The sponsor was Falstaff beer. I eventually found and tried Falstaff in my early twenties. Mickey Mantle was the biggest star of the New York Yankees. He struck out a lot, but always seemed to hit the late inning home run to salvage the game for the Yankees. He was my first hero and when he died it was a notable event in my life. Other stars at the time were pitchers Whitey Ford, Bob Turley, and Don Larson, first baseman Moose Skowron (from Austin Minnesota), and Roger Maris who broke Babe Ruth's single season home run record. Mickey Mantle hit over fifty home runs that same year. The Yankees won a lot and I became a loyal fan. Little did I know that fifty some years later I would have a disease made famous by Yankee Great Lou Gehrig.*

Randy also started watching daytime television. He emailed a friend:

*Yes I spend too much TV time. That and the Internet. I like to catch Gunsmoke at 11:00 am. The rest of daytime TV is pretty brutal...Bonanza runs after Gunsmoke but is usually pretty stupid. I pick it up with an hour of King of Queens at, I think at 5:00 pm and then Seinfeld for another hour which takes us into some movies or now American Idol.*

Randy liked to say that his grandson, Gus, had Batman for a hero, and that he had Matt Dillon. He joked that Dillon got shot all the time, but was always good to go the next day on the show.

A month after Randy retired, we arranged for home health care. The services were limited to a physical therapist twice a week and a CNA twice a

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week to shower Randy and stretch his muscles.

The first day the CNA came, Randy asked if she would look at a sore on his behind that he worried was a pressure sore.

Her response was curt. "That's not on my list," she said.

Randy was confounded, and after she left he called the home health agency and told them that he didn't want her to come back.

The second CNA was good and Randy liked her. She was the one who loved the "Butt Quack" boxers.

At that time, Randy did not like getting up early, so I went to work and then came back home mid-morning to get him out of bed and into his wheelchair, then from the wheelchair onto the toilet, then back into his wheelchair, then from the wheelchair to the recliner. Then I set up his surroundings so that his computer, the TV remote, his iPod, his phone, his asthma medication, etc., were within his reach. I hurried back to work and then I would run home from work at lunchtime to feed him.

My boss, Attorney Rita Raihle, was more than accommodating with my situation, and never objected to any time that I needed to be away from the office. Still, I always tried to be out for lunch for only an hour. Since my drive to work took only twelve minutes, it wasn't a problem getting home, getting Randy fed, and getting back to my desk in an hour's time - except when Rainier cherries were in season. Then, lunch time seemed interminable. I would pull the stem from a cherry, put the fruit into Randy's mouth, wait and wait, and wait some more while he chewed. Then I would hold my hand out for him to spit the pit. He loved the cherries so much that I would have to stand beside him and exercise supreme patience while he ate his fill.

We stayed close to home through the fall and early winter of 2010. Eau Claire had a big snowfall in early December. It took Chad and me the entire weekend to shovel and blow the snow. In addition to the driveway, we had to clear the long ramp of snow and ice for Randy to access both levels of the house. We had the lower level set up for sleeping and spending the days, but we ate the evening meal in the dining room on the main floor. I always worried that his wheelchair would slide backward and perhaps tip over on the slick ramp, but that never happened. And, even on the coldest Wisconsin days of winter, Randy wore only his underwear under a blanket when he wheeled up the ramp.

I am certain that this will offend some, but when Randy said he wanted to come upstairs to eat, Chad and I would tease and say, "Quick, shut the drapes so the neighbors won't see that we have a cripple in the house." Randy laughed at that.

Randy never lost his sense of humor. After he was confined to the wheelchair he began to gain weight and his fingers swelled. I told him that

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he should take off his wedding ring before we had to call the fire department to saw it off. He worked it off with soapy water, handed it over to me and said, “There! We’re through!” And in the midst of all the bad stuff, we laughed. We found ourselves laughing quite a lot; many times at things that were not funny at all. One of my journal entries of April, 2011, was:

*I found out that some people, including others with loved ones who have ALS, are uncomfortable with how openly Randy and I talk about his/our issues with ALS. And some are shocked at our sense of humor about it. But, my gosh, we have to laugh sometimes. Besides, Randy was the one who suggested I put him up for sale on Craig's list .*

After I had been at my job for a year, I mentioned that I had earned a week’s paid vacation.

Randy said, “Oh, and I heard you are going to Hawaii.”

Since Randy brought up that idea, Chad and I teased that we were indeed going to Hawaii. I said, “Well, Chad, what are we going to do with your dad?”

Randy joined in on the plotting and planning, and we finally decided that we could leave Randy in the basement with an open 50 pound bag of dog food and a 5 gallon bucket of water.

It was all in fun. And Randy always got a kick out of the teasing.

In fact, some of the funniest ideas came from Randy, himself, but he would not want me to write them down, as they could cause hurt feelings.



*Snowfall of December 2010. It took all weekend for Chad and I to shovel and snowblow.*

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Our grown kids and their families came to our house for both Thanksgiving and Christmas in 2010. I noticed our 10-year-old grandson, Paul, closely observing Randy. When I was alone in the kitchen, Paul came to me and asked questions about Randy's condition. I explained about ALS, and how the muscles had stopped working in Randy's feet, legs and right arm and that the muscles in his left arm were getting weaker. I told him that eventually the muscles in Randy's mouth and throat would also stop working, and then, when his diaphragm stopped working, we would have to say goodbye to Grandpa and let him go to Heaven.

With more passion than I had ever heard from that child, Paul said, "I wish there was a cure for ALS!"

After the holidays, Randy felt depressed. In early January, 2011, he posted the following on the ALS forum:

### ***Point of depression***

*I think I have reached the point of progression where I am chronically depressed. My legs are useless and I can't raise my right arm very high. I need help getting in and out of bed and off the toilet, and need bathing assistance. I can't turn in bed without the hospital bed rails which means I cannot sleep comfortably anywhere but home. My butt is chronically sore with the threat of pressure sores and simply repositioning is a struggle. I'm getting home health care, but this can end if skilled services are no longer approved. We are whittling away our savings for van, ramp, and now big bathroom remodeling project.*

*My wife works out of the home and one son lives with us working on the phone and computer for his job. I feel guilty asking them for the littlest of things and my wife is very tired working all day and then dealing with my needs.*

*One can spend only so much time on the Internet or watching TV. My relatives do not live close so visits are sporadic.*

*Just venting....but can anyone identify?*

As Randy's muscles deteriorated and his functionality decreased, he turned more inward. In February, 2011, he posted the following on the ALS Forum:

### ***Positives***

*ALS is a struggle and is depressing. As I continue to lose function, it's easy to dwell on the negative aspects of this disease. I have discovered, however,*

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*there are a couple of positives for me.*

*I look out the window this morning in Wisconsin and see the large gently falling snowflakes with my pine trees in the backdrop. This is beauty in nature that I can now savor instead of worrying about things like driving on slippery roads or cleaning up after the snow storm.*

*I notice the beauty in nature all the more because I now spend so much idle time caused by my immobility. I know the birds that frequent my backyard...blue jay, cardinals, yellow finches, a crow and many others. My backyard is also blessed with an integrated squirrel community of grey, black and white squirrels. Until recently I did not know that white squirrels existed. I've watched them prepare for winter by acrobatically snatching crab apples from my tree and hiding them in places only they will remember.*

*As my physical abilities deteriorate, I am more and more dependent on other people for even the most basic of needs. I am a control freak who finds this experience humbling. Maybe this is a life lesson that I needed.*

*Can anyone relate?*

One of Randy's postings generated a long thread of responses, as the ALS patients shared their thoughts and feelings. Randy started it with this:

### ***Things I've Learned***

*Without ALS I'd likely never have learned:*

- *Just about anyone can safely park in a handicap space*
- *Doctor and dentist offices aren't ready for nonambulatory people*
- *How expensive wheelchair vans are*
- *The obscene profit margins on durable medical equipment*
- *How to eat with my left hand*
- *That my arms are about six inches too short*
- *How powerful a force gravity really is*
- *You cannot easily slide on bare skin*
- *How uncomfortable lift recliners really are*
- *What a palliative care nurse does*
- *Men get yeast infections*
- *The name of the sacrum bone*
- *What a condom catheter is*
- *Bedbath is a misnomer*
- *How really wonderful it feels to have water running on your head*
- *Private parts easily become public parts*
- *Sleeping on one's side is (was) wonderful*

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- *The truly therapeutic value of the human touch*
- *Who my real friends are*

*Just sharing.....*

May of 2011 was a pivotal month. I came home from work on the 9<sup>th</sup> to find that home health care had discharged Randy effective IMMEDIATELY! They said they could no longer justify their services as Randy was not rehabilitating, and that he would need hospice care from here on. We did not have hospice lined up yet, nor had we interviewed any private care home health workers, and I would not have been comfortable hiring one blindly. Needless to say, we did not choose Hospice from the same facility we used for Home Health.

Within 10 days, we had a hospice team from St. Joseph's Hospital in Chippewa Falls. Randy was uncomfortable at having a new Aide who would get him out of bed and would shower him, but when he indicated his discomfort to her, she made him comfortable when she matter-of-factly said, "It's not my first trip to the rodeo."

One day I came home for lunch and found Randy on the toilet, his Aide brushing his teeth as he sat there. I stood in front of him and ate my lunch while chatting with him. There was no dignity left for Randy.

Randy emailed an old friend about having hospice care:

*yes, hospice is a frightening word...not feeling good about that at the moment...i don't want to die any time soon...my aide is only 31 but very capable and comforting...nurse and social worker are very nice too...i can barely use my arms and need to be hoier transferred on and off toilet, shower chair, wheelchair and bed...need to be fed, dressed and bathed...can't brush teeth, scratch scalp, or wipe butt.*

Randy received Hospice care three days per week, and he always looked forward to the visits from the nurse and social worker. They were people who, unlike me, had a special calling for caregiving. We also hired a nursing student to come in on the days we did not have Hospice care to get Randy out of bed and showered. This nursing student also helped him with emailing once his hands weakened, and she read to Randy the book I had been writing about my grandparents.

It was at this time that Randy finally got his custom-made wheelchair. He was right-handed, but had lost most of the function in his right hand, so the joystick was installed on the left. We learned the very first day that he should turn the machine off before I leaned in for a hug; a slight bump on

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the joystick caused the chair to ram into my leg. Right after that, Randy turned the chair and pushed too hard on the joystick and put a hole in the wall with the footrests of the wheelchair.

Another time, Randy ran over my toe with the chair, and I lost the toenail.

After that, I always asked if the power chair was turned off before I approached. The great thing about the custom-made wheelchair was that he was comfortable for longer periods of time. Prior to that, he had used a loaner power chair, and had to be readjusted every 40 minutes. Many times, finding comfort involved the slightest adjustment of his position; other times, finding comfort was elusive, and required a lengthy series of readjustments. The easiest adjustment for me to perform was when he reclined the wheelchair all the way back so that I could get behind him and pull him up under his arms.

At the first ALS Support Group meeting we attended, Stan said that if he had to have a terminal illness, he preferred ALS over cancer, because ALS patients didn't have the pain that cancer could cause. For the most part, that was true for Randy. However, overcoming discomfort was an ongoing battle.

Randy described his condition as it was the end of May 2011 in a fund-raising letter to our families and friends:

*May 30, 2011*

*Greetings,*

*It has been 16 months since I was diagnosed with Amyotrophic Lateral Sclerosis (ALS). ALS, also known as Lou Gehrig's Disease, is rapidly degenerative and always fatal. 50% of people with ALS die within 3 years and 80% die within 5 years. I have lost the use of my legs, I cannot sit upright unaided, and I cannot lift my arms. My fingers are beginning to curl and soon I will lose all use of my hands. It is failure of the breathing muscles that ultimately causes ALS death. My lungs are affected and I sleep with a Bi-pap machine which helps me breathe.*

*Approximately 5,000 people are newly diagnosed with ALS in the United States annually. They are affected physically, emotionally, and financially. New equipment such as power wheel chairs, walkers, shower chairs, handicapped accessible vehicle, transfer equipment like Hoyer Lifts, or hospital beds with specialized mattresses are needed. Bathrooms must be remodeled for handicapped accessibility, and ramps must be built to get in and out of homes.*

*The ALS association provides much of this equipment free to patients. I myself have received a varying air pressure mattress, a loaner power wheelchair, a manual wheelchair, a shower chair, lift recliner, Hoyer lift,*

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*standing pivot discs, and similar items from the ALS association loan closet. The Northwest Wisconsin ALS Chapter also holds support group meetings for people like me and others in the area. Once a month we get together to talk about the disease, share information about how to cope with the disease, and to give we patients and caregivers an opportunity to understand that we are not alone. We give each other emotional support along with advice. By making contributions to the ALS Chapter, you can help provide support to us which we continue to benefit from. If you care to make a contribution of any amount, it will be well utilized and greatly appreciated.*

*Sincerely,  
Randy Studier*

By mid-2011, Randy's life was spent mostly with his laptop computer. He played online bridge, worked on online jigsaw puzzles, researched, and emailed friends and family. He switched from a laptop to an iPad when the laptop became too heavy for him.

Then, one day, he asked me to hand him the iPad. I watched as he fumbled to situate it on his lap, then as he tried to move his fingers to turn it on. I held back tears when he said, "Take it. I can't use it anymore."

The next day, he asked the hospice nurse if it would be okay for him to spend all his time in bed. She said he should do whatever was comfortable for him.

Our friend, Marv Bednar, told me how his heart sank the day he came to visit, ran down to the family room, and found Randy's wheelchair empty. He knew then that the end was near.

I asked Randy if he wanted the hospital bed brought into the family room, but he didn't. His brother, Dan, came and installed the television on the bedroom wall so Randy could comfortably watch from his bed.

Randy commented on his condition in August in this email to a friend:

**To:** *patricia willson*

**Sent:** *Mon, August 8, 2011 6:34:52 PM*

*Hi Patti,*

*I can't type anymore so I have to wait for help with my emails. We're just kinda waiting for all this to get done with. Chad will move out at that point. And Sue can get back to somewhat of a normal life. I'm still declining. I have almost no use in my hands and arms, and my neck is getting weak. My breathing is still declining. That's the good news. The bad news is, I still got a ways to go. I say that with a bit of humor, but this is really getting difficult.*

*Sue is working mornings in the office and afternoons at home. I'm sure she's going through some of the same things you had to with David. Life really sucks at times. Send Sue an email when you get a chance. She'd like to*

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*bear from you.*

*Love, Randy*

Around that same time, I emailed my siblings the following:

*Grandpa Albert wrote that he was but a mere child of five years when he first experienced the manifold sorrows of this world. I keep thinking of that, probably because I am in the midst of one of those manifold sorrows. I was talking with one of my sons and I told him how I missed the feeling of happiness or joy - that even when I sit on the deck on a most beautiful day, no comfort comes to me.*

*Randy's legs, arms and hands are now useless. We spend all our time attempting to make him comfortable in his wheelchair or in his hospital bed. We are up many times each night to reposition him or give him medication. He is on Hospice Care and has a nurse here every morning so I go to the office in the mornings only. His breathing muscles are becoming alarmingly weak. I believe it is possible for him to die at any time now. We have his funeral planned.*

*My employers could not be more supportive of me and this situation. I can work as much or as little as I want - I can work from the office or from home - or I can work none at all.*

*I have become acutely aware of how much I like to look into my husband's eyes (or could it be that I love how he looks at me with those eyes?) I will miss those kind eyes.*

Toward the end of August, 2011, after a night of being up 8 times to tend to Randy, I went to work in the morning, entered Rita Raihle's office, dropped into a chair, and told her I couldn't come to work anymore. She graciously offered to let me leave right then, but I told her I would finish out the week.

The following Monday, I joined Randy in the bedroom, and that room became our universe. My bed was on one side of the room; his hospital bed on the other. We watched Gunsmoke, Bonanza and Cash Cab. In the evenings we watched Reese Witherspoon or Drew Barrymore movies. I handled the laptop whenever Randy wanted to research something. I left the room only to Hoyer-lift Randy across the hall to the bathroom, or to run upstairs for food. We entertained visitors in that room.

During the month of September, 2011, Randy dictated letters to be delivered after his death. His friend, Laurie Hennen, drove to Eau Claire from the Twin Cities several times to type up the letters Randy dictated for our sons and daughters-in-law; for his siblings and mother; and one for me. I helped with letters Randy wanted to leave for his closest friends, Jim and

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Jeannie Sunnarborg, and one for his high school music teacher, Laverne Walheim, and a few other people who had touched Randy's life in some special way. In the letters, Randy told of the things he appreciated about each person, and ended with his wish for each. The letter he left for me follows:

*Dear Sue,*

*So I know you know the story . . . But I am sooo glad that we met, that you were so good looking and that you were available. 43 years is a long time, but I am grateful for all the things we have had together.*

*You are a great mom and an even greater grandma. Our kids and grandkids are lucky to have you. You made a great hockey mom and a great hockey grandma. You have always taken great care of our home and I really appreciated it. You have a strong work ethic and have passed down wonderful traits to the kids.*

*Thank you for taking care of me during the past few years. You have been a faithful and loving wife. There are times when I probably didn't deserve you. Thank you for sticking with me.*

*What I love most about you is the mom that you have been to our boys. Be proud of what you have accomplished with them. My wish for you is that you complete your book. I know you can do it.*

*I love you with all my heart.*

*Randy.*

Eating and swallowing and breathing became more difficult by the day. Randy began to rethink his earlier decision to forego a feeding tube. Though I doubted the surgeon would perform the surgery at that time given Randy's breathing difficulties, I told Randy I would take him in for it if he wanted, but he finally decided that he did not want to prolong the ALS by that means.

I began to puree his food. Our friend, Dianna Bednar, brought a delicious lasagna for us. I pureed that for Randy. He told Dianna her lasagna was awful.

One evening I asked Randy if he would like me to make him a malt. I was mixing it upstairs when he called for me over the baby monitor. I hurried downstairs to find that he only wanted the television channel changed. I ran back upstairs and finished the malt. I took it down to the bedroom, set it on the bedside table, elevated the head of the bed, removed the BiPAP from Randy's face, tucked a towel around his neck and chest, then gave him a spoonful of malt. I could only laugh when he complained that it was too melted.

Concerned that Randy was not taking adequate nutrition, I bought a six-pack of Ensure. Every day I asked him if he wanted some. He always

refused.

I need to insert an anecdote about my mother here: My mother never swore or cursed - except for when she had chemotherapy and had to drink Ensure. She said that the Ensure tasted like shit. That became a family story simply because Mom never talked like that.

When Randy could eat little else, I became more insistent that he have some Ensure. He finally said, "I just can't understand why you want me to drink that stuff when you told me your mother said it tastes like shit!"

I never could convince him to try it.

In early October, 2011, Hospice sent over a speech pathologist to assess Randy's swallowing capabilities. Randy was worried about aspirating food or liquid into his lungs, which can cause pneumonia – a common cause of death for ALS patients. Interestingly, liquids were the worst problem for Randy. The speech therapist brought a substance called Thicket, which thickened liquids to pudding-consistency. She followed up her visit with an email:

*Randy and Susan,  
Here are a few basics with swallowing safely.  
Safe Swallowing Guidelines:  
Sit up at 90 angle to minimize aspiration.  
Small amounts at a time: ½ to 1 teaspoons.  
Swallow what's in mouth before adding more food.  
Alternate food and drink.  
Remain sitting upright for 30 minutes after meal is finished.  
Wet sounding, gurgly voice suggests food/ liquid going down on vocal cords.  
Thicket can be used to mix up a pudding thickened consistency. Use a spoon  
to place on the stronger side of the mouth.  
I will talk to [the hospice nurse] about seeing you for one to two additional  
visits.  
Take care.*

As Randy's food intake decreased, he fretted about becoming constipated. I was certain that he was eliminating an amount adequate to his intake, yet he insisted on having me give him suppositories. The problem with that was if I gave him the suppository while he was in bed, he wouldn't be able to hold the bowel movement long enough to get to the toilet. And if I gave him the suppository when he was over the toilet, he wouldn't have been able to hold the medication in long enough to be effective. It was a tense daily discussion.

The toilet, those last few weeks, became too uncomfortable for Randy to sit on, so he used the softer shower chair (pictured on page 33) with an attached dish-pan-like container for toileting. One early morning he sat on

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it for three hours, convinced that he should eliminate more than he had. I argued that he had sufficiently defecated, but he wouldn't budge. When the hospice nurse arrived that morning, she said it wasn't good for Randy to be sitting on the shower chair for that long. She provided bed pads, and I purchased adult diapers.

I was relieved to end the trips to the bathroom. From the time I decided I would be Randy's primary caregiver, I was determined to do the best job I could for him. Still, there were times when my patience was merely an act, and not what I was feeling inside. I found that writing down my thoughts and feelings was usually sufficient to get me through the trying days. The frustration and fatigue I felt at the time that we ended bathroom visits is clearly revealed by this journal entry:

*I feel like a jack-in-the-box: he says, scratch my head; turn me over; get a wet rag and scratch my nose; too cold; too hot; take me to bathroom; take me to bathroom; take me to bathroom.*

My sister and brother-in-law, Pat and Rick, came to visit the weekend of October 15, 2011. The weekend was remarkable and chilling at the same time, because we recognized it as the "last rally" many people have prior to dying. Pat described it in an email that she sent to all of my siblings:

*Monday, October 17, 2011 9:04 AM*

*We had an awesome weekend, unbelievably!*

*Friday night Randy rested and watched TV while Sue, Rick and I sat at the card table next to him playing some games.*

*He used the bi-pap very little the entire weekend and he had a strong voice and actually talked quite a bit.*

*Our highlight was Saturday night when Randy decided to play Shanghai! We managed to play 2 games and although the first game Randy came in last place he played 2 awesome games considering he needed to remember everything because he could not see everything on the table from his angle and he was unable to shuffle his cards around during each round. He would have liked a third game but it was already one a.m. so it was decided to get to bed. As it turned out Randy and Sue were up pretty much the whole night on Saturday that we probably could just as well have played that 3rd game!*

*Sue is busy busy busy tending to Randy.*

When I described that weekend to the Hospice Nurse on Monday, she agreed that it sounded like a final rally.

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The last few weeks of his life, Randy frequently asked to have his pulse taken. He had found information that an increasing pulse rate was an indicator of impending death. One day, Chad, Brittny, and I surrounded him, each of us desperately trying to find a pulse on some part of his body, none of us finding one, until Randy became frustrated and said, “Good grief, it’s not rocket science!”

At that point, Chad quickly said, “It’s 70.” We had learned that “70” was a good, healthy, resting pulse rate. I don’t think Randy was fooled.

Ever since, when Brittny and I hear the phrase “it’s not rocket science” we remember that moment.

Randy and I talked about his impending death. A lot. Randy said that he wanted to be cremated, but I have such a strong conviction about traditional Christian burials that I told Randy it would be emotionally difficult for me to honor that wish.

He said that he hated the thought of people staring at his body in the coffin, but that, upon his death, it would matter more to me than him, and that I could bury his body.

He chose the music he wanted at his funeral, and the place he wanted to be buried. He chose the hymns “How Great Thou Art,” “Amazing Grace,” and Vince Gill’s “Go Rest High on That Mountain.” He asked our son, Jason, if he would read 1 Corinthians, Chapter 13 – the “love chapter” – at the funeral.

Knowing that people would need to be notified upon Randy’s death, I asked our oldest son, Chris, to take care of that. He agreed, and emailed me:

*Friday, October 14, 2011 9:41 AM*

*I can call everyone and would be honored to – it may be best if I do it.*

*We can talk about it when it’s time.*

*I am still angry, sad, devastated, etc...about this disease. I’ve changed my prayers from asking for healing to asking for mercy. I think he has had enough.*

*We’ll talk soon.*

*Chris*

## 10 FINDING FAITH

*"It's kind of hard to ride the fence between hoping to get better and getting ready to die."  
~Randy Studier~*

**A**s soon as Randy was diagnosed with amyotrophic lateral sclerosis, he was forced to face his mortality. At first, he felt compelled to look back on his life. He wrote:

*You have to wonder what it's all about. You realize that the string of years, months and days are shortly going to cease. Now that the future will soon disappear, you know that goals are all now short term, relationships must be wrapped up, and your legacy is pretty much determined.*

*Reflecting on my life, I think about a lot of partial successes. I think about relationship opportunities that I mismanaged and the struggle to have the confidence needed to enjoy a lot of things. It's strange, but my mind gets drawn to specific memories in my youth, and I wish I had done things differently. What I'm saying is that I'm going to leave this earth without wonderful feelings of having the happiness and successes I believe I could have had. Maybe it's the competitiveness inherent in our immediate birth family, I just don't feel justified. Looking back, life had its moments, but mine was a mess from a number of angles. And what a depressing way to bow out I'm looking forward to! I've pretty much worked my whole life...bees in the summers...year-around GMI (wish I never heard of that place)...my whole career going job to job and moving the family. I am now not able to enjoy retirement. I'm maybe a negative person, but it's been barriers at every turn.*

*What mark do you leave? Who and what did you influence? Did it really matter that you were here in the first place?*

*Certainly you are the sum of your memories, but they will disappear with your physical being. Others will remember you in differing ways*

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*depending on your experiences and interactions with them.*

*What will you leave behind? Your mate who can live on as she has always done with your influence fading as time keeps flowing. Your children, who survived to adulthood regardless of your mentoring, will not be bound by wondering what you might think of them.*

*What do you consider your contributions and influences that you are leaving behind? Do you care or for that matter does anyone?*

*It is not that I have not had successes in life, because I had several good jobs, a faithful, loving wife, and four sons who love me. Now that I am facing my impending death I realize that it is probably more important to enjoy your relationships and not worry too much about making a mark in this world.*

As mentioned previously, Randy had an acute analytical mind. I believe that trait served as a stumbling block for him his entire life in regard to his faith in God and Christianity. A study by Will M. Gervais and Ara Norenzayan titled *Analytic Thinking Promotes Religious Disbelief* reported in Science magazine on April 27, 2012, suggests that very idea. (Vol. 336 no. 6080 pp. 493-496, DOI: 10.1126/science.1215647).

In spite of being raised in a Christian church, Randy always questioned whether or not it was real. He told me that he wanted to be in control of his own life, and not turn it over to God, as Christianity teaches.

When he was diagnosed with ALS, however, he realized that he did not have control over his own life, and that he could no longer depend on himself for his wellbeing. He had to seriously consider what would happen when he died. He wrote some of his thoughts in an email to my siblings dated March 24, 2010:

*I think a lot about the big picture and life after death. I know that things here are not so important. I've been blessed with Sue and all of you (her siblings). The Paul W. Schmidts are a very united and caring family. Sue is a blessing above and beyond what I deserve.*

*I'm still trying to live a "normal" life and likely won't give up total hope for remission until I get much worse. I don't know what plan God has for me. I've always been a person who has a hard time giving control to others, and maybe this is a lesson in submission. How this will progress is hard to predict. But I know it's almost certain that tougher days are ahead for Sue and me.*

Our friends and family, from all denominations, told Randy that they were having their churches pray for him. He expressed appreciation for that. Many brought him resources, e.g., my sister, Shari, brought him a Bible that was arranged to be read in its entirety within one year; his sister, Jane, brought a set of Bible CDs; his friend, Dennis Dunham, brought him

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books about the teachings of the Apostle Paul; others shared their personal beliefs.

His high school friend, Ken Cafourek, visited one day. Randy told Ken that he had experienced a period of anger at God because of the ALS, but he had been able to overcome blaming God for his fate. Ken asked Randy if he could share his beliefs, and Randy was receptive.

Randy and our friend, Jeannie Sunnarborg, spent an afternoon hashing over the question of whether Christianity was real. When Jeannie came back for her next visit, she said that she had the answer. She said that she had been at home, and that the answer had just come to her. "Of course it's real!" she said. She asked Randy if he believed that, and he said, yes. "Why do you believe it?" she asked.

"Because you told me," he said.

Marv and Dianna Bednar visited often and spoke of their faith and beliefs. I remember Randy saying "thank you" to them after one discussion.

When we needed to remodel the bathroom, Randy assembled a list of contractors to interview for the project. The first one to come over, Ben McCune, asked Randy why he was in a wheelchair. Ben then told us how his daughter had leukemia and had almost died, and how that experience had taught him how to really pray. He asked Randy if he could pray for him. Randy was receptive. Ben got down on one knee, placed his hand on Randy's leg, and prayed. Randy hired him without interviewing any other contractors.

One day the question of whether the hereafter was real came up when the hospice nurse tended Randy. She told him that she had seen enough end-of-life moments to convince her that Heaven exists.

Randy's search for faith extended into his online world of the ALSForum. He made a special connection with one lady who also suffered from ALS. When he wrote to her of his dissatisfaction with how he had spent his life, she responded:

*Dear Randy,*

*. . . If you aren't offended, I would like to comment on your disappointments. When we die, there will be no satisfaction in what we mastered here. Whether as an engineer or as a musician, it will not be something to take with you. The two things that matter--the only two are these: Love the Lord your God with all your heart, and love your neighbor as yourself. You have Sue with you. Be interested in her day when she comes home, and smile and tell her how much you love her. It is NOT too late. This time, for however long it lasts, can be the best time in your marriage. If you have hurt her in the past, ask forgiveness now. And if this hard push to read the Bible in a year discourages you at any point, I will send you an easy to read regular Bible. That's how strongly I feel about your reading the Psalms and New*

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*Testament. Just let me know.*

*I know that especially for men, the value placed on career is enormous. . . .I urge you to let go of your career and to put all your feelings of failure aside, and focus on knowing the Lord and also on Sue. I guarantee it will make her life easier if you can do this, since it is difficult to have a depressed husband. There is joy in knowing the Lord, Randy.*

*Hugs and very best wishes for a good day today.*

Randy asked me to download my Christian music onto his IPod. He also had me purchase and download from iTunes his favorite old hymns as they came to mind. He listened to the music more and more during his decline.

He also listened to the Bible on CDs that Jane had provided. He expressed frustration about not knowing enough of biblical history to make sense of some things. Again, that was his analytical mind at work.

During the last couple weeks of his life, he focused on the book of John. He then asked me to have the Hospice Chaplain come to the house. I left the two of them to visit alone, so I do not know what was discussed. I heard later from Hospice that the Chaplain said Randy was a most impressive man.

Finally, after all the months of searching for faith, Randy told me, "I am relying on John 3:16."

The verse is this:

*For God so loved the world that he gave his one and only Son, that whoever believes in Him shall not perish but have eternal life.*

Amen.

## 11 THE LAST FIVE DAYS

*"You still have quality of life if you can sit up without falling over, breathe without assistance, and eat." ~Randy Studier~*

**O**n Friday, October 21, 2011, Randy settled down to die. He could not sit up without falling over, breathe without assistance, or eat.

That morning, Randy asked me to tell the people who planned to visit to not come. I told him that we would notify his friends, but that our sons, Jason and Josh, were on their way. He grimaced.

I said, "Hey, you can play Euchre with your sons tonight."

He responded, "Yes, but I'm going to try to die first."

"Oh, Hon, why would you say such a thing," I asked.

"Because I don't feel good," he said.

He refused the BiPAP all day long, hoping to die.

At 3:00 a.m. he had asked me to put him on the toilet. Over the next 12 hours, he had me Hoyer-lift him to the toilet 8 more times. He was terribly exhausted, and so was I, so I finally refused to take him out of bed anymore. "I will clean you up," I said.

Once the boys arrived, I retreated to allow them alone time with their dad, and intruded only when summoned to do nursing duty. When Jason and Josh were ready to leave, I joined them in the bedroom and found Randy with a plastic bag of ice cubes on his head.

"What's with the ice?" I asked.

"It makes me feel better," Randy said. From that point on, he wanted a bag of ice on his head.

Throughout the day on Saturday, October 22, 2011, Randy asked for morphine as often as he could have it. After each dose, I asked if he wanted

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to watch t.v. or have something to eat, but he would only say, “Ice on head; mask on (BiPAP); lights off.” He wanted quiet and dark.

Then, after his 10:30 p.m. morphine on Saturday, he refused all medications for the next 24 hours.

On Sunday afternoon, October 23, 2011, while I hovered over him, he said, “Sue, I will see you in heaven.”

I took his hand and said, “When, Hon?”

“I’m going tonight,” he said, “but I won’t see you for a long time.”

That evening, when I tucked him in for the night, he said, “You can give me extra morphine if you want.”

I understood what he was saying. “Oh, Hon,” I said, “I can’t do that.”

“I’m praying to die,” he said. “I’m miserable. I feel like I am drowning.”

Monday morning he could barely speak above a whisper. The hospice nurse and I leaned close to his face to hear him.

“How long will this go on,” he asked.

“That’s hard to predict,” the nurse said.

“I don’t want to prolong it,” Randy said.

“Randy,” the nurse said, “I don’t know how you are still with us. For months now I have heard only faint, short puffs of breath in your lungs. I don’t know how you are doing it.” She then asked several probing questions, wanting to be certain that she understood what Randy was saying. “It will depend on your intake of water,” she said. “If you drink water, you will probably live another week. If you don’t drink water, you will die this week.”

When the nurse was leaving, she asked me if I also had understood that Randy wanted to be done with it. I said yes. She then called the pharmacy for a prescription that would increase the Fentanyl dose so that Randy would remain as comfortable as possible.

As soon as the nurse left, Randy asked for water. I placed the long straw into his mouth. He sucked up a mouthful, and then deliberately spit it out. He never swallowed another drop of water.

Tuesday morning, October 25, 2011, at 5:30 a.m., I began to swipe choking phlegm from Randy’s mouth with a washrag and give him water to swish and spit. The phlegm production went on for about five hours, until the heavier dose of Fentanyl took effect, and Randy was able to sleep.

That evening, after Chad and I tucked Randy into bed with nine pillows and the BiPAP, I took Randy’s hand and these words came out of my mouth, “Some people think that when you die Jesus meets you. Some

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think that family members meet you. So, if you see Jesus, go with Him. If you see your sister, Nikki, go with her. If you see my mom, go with her. If you see your Uncle Franklin (name changed), run as fast as you can the other way.”

Randy laughed as best he could.

As Randy slept, I logged onto Facebook, and his sister, Jill Hagen, initiated a chat with me, saying that she had a heavy heart for me and Randy that day. I told her that Randy could pass on anytime. But I didn't really believe it in my heart.

At 2:00 a.m., he called my name. I went over to him and leaned in close to hear what he said. It was difficult to understand him.

“Did you say to put your clothes on and then take your clothes off?” I asked.

“Yes,” he said.

Confused, I glanced over at the closet, which was the direction he appeared to be looking.

“Okay, I will help you with that,” I said. I checked the medication log and told him he could have morphine or the anti-anxiety drug if he wanted.

He declined.

Exhausted, I fell back into bed. When I woke five hours later, I instantly knew he was gone.

It had been 21 months since his diagnosis of ALS.

After the funeral home removed his body, and Chris had called our list of people, I let my other friends know what had happened by posting on Facebook:

*My beloved Randy went to Heaven last night. Thanks to all for your love and support and concern throughout this journey. Sue*

Ten-year-old Grandson Paul responded:

*why can't they find a cure to A.L.S.*

## APPENDIX

After Randy's body was removed from the home, I went to my computer and found an email that Brittany had sent the previous evening. She had asked me to read it to her Grandpa, but I never got the chance. She gave me permission to publish it here. This is the email:

*Hey Grandpa,*

*I've been missing our weekly visits. I wish I wasn't so busy so I could've come out more lately! School is starting to slow down for me now. I only have 2 weeks left of seeing patients and after that I'm done with all my patients! Then I have my first of three exams to get licensed in the middle of November. I start my internship in January. I get to intern at the U of M for 5 weeks and then my dentist in Woodbury for 3 weeks. I'm excited to intern at the U because I'm going to pursue dental school there. Hopefully the Studier brains help me get accepted right away. By the time I become a dentist it'll be about 6 or 7 years from now, but I know I will be happy.*

*I never thought I'd have conversations with you about my boyfriends, but I've gotta tell you, I've enjoyed talking about Andrew with you the most. I'm glad you watched one of his games with me online. We finally talked again last week for the first time in 2 months. He's acting like a stupid boy, but I think life's too short to hold a grudge so I'm going to give him another chance since I REALLY like him for some odd reason. I think I might fall in love with him. Don't let*

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*anyone know I said that! And if it doesn't work out with Andrew, I plan on finding a really cute, smart dentist!*

*Thanks for being such a cool grandpa. I've enjoyed all the things we've done together. Like buying those huge ugly goggles for the reunion, playing piano and guitar, going on the Wild Thing sitting in the back, watching Gunsmoke, and watching chick flicks (especially Sweet Home Alabama). All your jokes always make me laugh, even if they're very inappropriate!*

*I'm going to miss you very much grandpa. Seeing you get sick is the hardest thing I've ever had to do. I'm going to pray and talk to you every day. I know you'll be my guardian angel and be with me always. I love you so very very very much.*

*Until we talk again,*

*Your number 1 grandchild, Brittny Marie*



*Brittney and Randy acting goofy. He frequently joked that he would like to go to a job interview like that. We laughed and laughed that evening.*

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### MEMORIES FROM CHRIS STUDIER

Posted by Chris:

Thu October 27, 2011

Dad,

I always thought that you would be with us for a very long time considering how many death-defying acts you performed here on Earth. I remember when you started that propane tank on fire at BAV and somehow managed to put it out with a paper napkin as I ran for cover; I remember how you ended up hanging upside down in your deer stand by your feet with your rifle in one hand and your other hand on a branch; I remember watching you roll down that rocky ski hill in the UP in July; and I can't even count the number of times you somehow managed to end up in the water during various fishing trips; but the challenge you couldn't conquer was ALS. I hope to someday understand how you were able to keep your sense of humor and upbeat attitude as we all watched this nasty disease take you from us. You were always supportive of your 4 boys whether they did things right or wrong. You were a great dad. I love you and miss you terribly.

Chris

MEMORIES FROM DIANNA BEDNAR

Marv and I have known Randy and Sue since 1983. Marv and Randy coached youth hockey together for a few years. We were stunned and sickened when they told us in 2010 that Randy had ALS. The two of them (Randy & Sue) shared this journey that simply amazed the two of us (Marv & Dianna). Their strength was powerful.

Randy and I emailed back and forth occasionally during his journey. Here are a few stories from Randy's ALS journey. This one came right after a visit Sue and Randy made to our place up north in May 2010.

*I really appreciate the thoughts and prayers. The bad thing about this disease is that aside from thoughts and prayers no one can really help me. I can go to a doctor, but all he or she can do is help treat bad affects or recommend equipment. I was pretty depressed yesterday because I hate being an invalid and I am sensing more progression. I'm still at point where I can do things, but am not at all looking forward to what is ahead.*

He responded to my reply in which I told him it was heart-warming to see the devotion between Sue (his little gumdrop) and Randy with this:

*Sue is my greatest comfort. I hope we can find ways to take some burden off her. It's only going to get worse as I continue to lose function. This disease really is a "beast." I can deal with death a lot easier than losing all my muscle function while still living. I look for news of a potential cure every day.*

This email came in October 2010:

*All my boys will be here to help and I'll be giving them fishing and camping stuff to split up. Now that's depressing in itself. Chris brought me one of those electronic picture displayers with about 200 pictures from our camping/fishing trips. Makes me cry because it's all over. Really that's what we did mostly as a family...Sue in the early years, but she quit going later.*

## HEADING HOME

Randy had a great sense of humor, which he maintained throughout his illness. Sometimes you'd just wonder where he came up with some of his comments:

*. . . do drop in, dew drop inn, anytime. I've been thinking about starting a wheelchair square dance club!*

December 2010 – Some words of wisdom that Randy shared:

*Yes, enjoy your time together and cherish every step you take. When you get out of bed in the morning remind yourself that "God has blessed me for another day." Sue and I are doing fine despite the ALS challenges.*

Tough decisions they were wrestling with:

*I don't like to think about the end of life decisions either and have been putting that stuff off. Do I want a "do not resuscitate" bracelet, do I want to be on a respirator, do I want a feeding tube. Other things we need to decide are where will be the funeral, where will I be buried, etc. I could leave those to Sue when they need to be decided, but we should at least probably have a burial plot. It's odd thinking about a funeral when you won't be able to experience it.*

Feb 2011:

*My lungs don't feel good today. I don't think the journey will last another year. Hard to say that, but I'm kinda pessimistic for the most part.*

March 2011: So one of the jokes I forwarded to Randy was not really a joke. It was interesting statistics about the human body including this fact - The average man's private area is three times the length of his thumb. And here's Randy's reply:

*gee whiz, I've always wondered why my thumbs are disproportionately long!*

Around this time Randy wasn't able to use the laptop or iPad anymore so occasionally I would call him when I was driving up to Appleton for

## Susan Studier

business. One conversation I will never forget was him telling me how he could never ever have made this journey without his “little gumdrop” Sue. She was so good to him and so strong. He was so grateful for their marriage and the years they’d had together and for their four boys and the grandkids.

We visited as often as we could and sometimes brought food. Towards the end I brought a pan of lasagna. Randy now needed his food pureed so Sue pureed the lasagna for him. The next time we stopped Randy told me my lasagna was AWFUL. I imagine! Pureed lasagna. But we laughed about it. He always laughed and made jokes.

Marv and I will always remember our last visit with Randy. We reminisced, shared some laughs and some stories about better times. We did most of the talking as talking was hard for Randy at this point. When it was time to leave I hugged him and said good-bye. Marv stood at the end of his bed and Randy choked out slowly “Good-bye Marv”. We knew it was the last time we would see him alive and it was heart-wrenching.

The four of us had shared our Christian beliefs, questions and doubts during this journey and we would share bible verses from time to time. The last thing I looked at on our way out of their bedroom was the bible verse hanging on the wall above Randy’s bed:

**<sup>9</sup>but he said to me, “My grace is sufficient for you, for power<sup>[a]</sup> is made perfect in weakness.” So, I will boast all the more gladly of my weaknesses, so that the power of Christ may dwell in me. <sup>10</sup>Therefore I am content with weaknesses, insults, hardships, persecutions, and calamities for the sake of Christ; for whenever I am weak, then I am strong. 2 Corinthians 12:9-10**

Randy died six days later. His example of grace, dignity, faith and humor in the face of death was powerful (as was Sue’s example too). He was a class act and we learned much from him.

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### MEMORIES FROM NICHOLE STAEHLING

“Bowana,” Uncle Randy muttered under his breath.

“What?” I asked.

My Aunt Sue, my parents, and I all looked up from our playing cards.

What a strange interruption in our card game, I thought as I looked at Uncle Randy across the table. I saw his eyes begin to sparkle and a great big smile slowly curl up his face. He knew he was on to something and was now committed.

“Bowana,” he said confidently, looking straight at me, “A bowana.”

“But I don’t wanna be a bowana,” I said, knowing it couldn’t be anything good.

Uncle Randy began to laugh, quite pleased with himself really. He found it absolutely amusing that even though I didn’t know what a bowana was, I sure didn’t want to be one!

A great deal of hilarity followed as further discussion during the continuation of our card game determined that a bowana was somewhat of an Amazon that did indeed wear pantyhose with one leg on and with the second leg dangling free out the other pant leg.

My uncle Randy brought so much joy with his grand sense of humor and his fabulous imagination. I will always treasure the memories of my dear Uncle Randy.

In loving memory,

Coke

## Susan Studier

### MEMORIES FROM ANGELA OLSON

What can one say about Randy? He was that older brother we all looked up to with great admiration. I loved his intelligence, his ability to maintain his composure in stressful situations, and, of course, his wicked sense of humor. Being seven years older than me made him all the more mysterious and added to his prestige as I didn't know him well enough to be aware of any of his faults. He set the standard for those of us who were younger and it was one that was impossible to attain.

My favorite times with Randy were as an adult carpooling to and from Mankato when he was teaching at the technical college and I was working on my degree at the university. He was "my" captive audience during those drives, probably the only times in my life I had him all to myself. He was always positive and always encouraging. When I expressed doubts about my ability he encouraged me by saying, "Don't worry. Just remember that you are smarter than ninety-eight percent of the people there." No matter how untrue that statement was, it set me at ease and gave me the confidence I needed.

It wasn't until Randy was dying that I realized that he couldn't solve all the world's problems. I asked for his advice, fully expecting him to be able to give me the answer to a situation that was breaking my heart when he said, "I'm sorry but I don't know what you can do."

Now that he is gone, how do I view him? Well, I can say that I have a great admiration for his abilities, his intelligence and sense of humor, but most of all I admire that way he could handle himself in a stressful situation. He faced a horrifying, terminal illness with more grace and dignity than I ever thought possible. Once again he set the standard for the rest of us.

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### SONG FOR RANDY BY JANE PECORA

#### I Cried

by Jane M. Pecora

When I was just a little girl, I cried when you teased me.

Yet I grew up with you in my heart, knowing you believed in me.

When you left home for college, I cried to see you leave me.

We raised our families far apart. Our lives were led so differently.

When I heard that you were sick, again I cried. It grieved me.

I held my hope in Jesus. My faith in Him relieved me.

But when you left us for heaven, great tears of joy I cried.

Knowing soon I would see you on the other side.

Knowing soon I would see you in the Sweet-By-and-By.

Susan Studier

DAUGHTER-IN-LAW BROOKE ASKED THE PASTOR TO READ  
WHAT SHE WROTE ABOUT RANDY:

I wanted to share some things about the man I was so lucky to have as a father-in-law. Most people I know don't like their in-laws and I can honestly say I adore mine. From the day I met Randy, I thought he was the coolest - playing guitar with his son. I loved how he always took the time to ask about what I was doing. He always made me feel comfortable and at ease. You could tell he was proud of you and loved you. His relationship with his sons was amazing. He was their father and best friend. We will be lost without him. I am so grateful for the time we had with him. He will live on in his sons and grandchildren and forever in our hearts. I hope he is enjoying the music in Heaven, I just wish he was still playing here. I love you Randy.

Brooke

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### EULOGY BY PHIL STAEHLING

Randy was my cousin, brother-in-law and friend. I love the guy. I knew him all my life, and stayed closer to him since we married sisters. I remember a day when we were in elementary school. Randy had stayed overnight at my house and, in the morning while we waited for the school bus, we played cowboys and Indians. I asked Randy which weapon he wanted. He chose the bow and arrow instead of the cap gun. I really wanted the bow and arrow, but had been taught to defer to others. Randy was good with the bow and arrow. He shot it into the air so that he hit me on top of the head, though I was hiding behind an obstacle. I remember the blood, but as was typical back then, my mother simply handed me a handkerchief to hold over the wound and sent me on my way to school.

Both Randy and I had prostate cancer in the recent past. Randy had his first, and he helped me deal with it when I was diagnosed. He was a smart guy who researched all his interests, and by the time I was treated for the cancer, he had a wealth of information for me.

Even as Randy was bed-ridden, he encouraged me about playing the cornet. He asked me to Skype him and play the horn for him. I asked him why he was still interested, and he said he was living vicariously through me.

Randy never lost his sense of humor, and still made us laugh throughout his journey with ALS.

Randy is OK now with God and healed of all because of what Christ did for us on the cross.



Funeral services for Randolph Martin Studier, age 63, of Eau Claire, WI will be held at 10:30 a.m. on Saturday, October 29, 2011 at Bethlehem Lutheran Church. Rev. Ronald Myers will officiate. Interment will be at Greenwood Cemetery. Visitation will be from 5-8:00 p.m. Friday, October 28th at Bayview/Freeborn Funeral Home and one hour prior to the service at the church.

Randy died of Amyotrophic Lateral Sclerosis Wednesday, October 26, 2011 at his home.

Randolph Martin Studier was born on August 18, 1948 to Rudolph and Anne (Kunkel) Studier. He grew up in Glenville, graduating from Glenville High School in 1966. Randy attended Kettering University in Flint, MI graduating with a degree in Electrical Engineering. He later received his MBA from the University of Minnesota-Duluth. On August 10, 1968 he was united in marriage to Susan Schmidt in Hayward, MN. The couple lived in Michigan for several years and later returned to Minnesota. Randy began his career as an engineer for General Motors in Detroit. He was then Regional Director for Minnesota Technology Inc. at UMD. Randy retired as an Outreach Specialist for the University of Wisconsin-Eau Claire's Continuing Education Department. Randy enjoyed

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hunting, fishing, camping, playing chess and had a great love for music. Blessed be his memory.

Survivors include his wife Sue of Eau Claire, WI; children, Christopher (Janine) Studier of Columbus, MN, Jason (Holly) Studier of Sun Prairie, WI, Joshua (Brooke) Studier of Milton, WI, and Chad Studier of Eau Claire, WI; grandchildren, Brittny, Gabe, Noah, Paul, Ellie, Sebastian, Elias, Annamarais, Leo, Niko, and Gus; mother Anne (Tony) Chavez; siblings Jane (Eddie) Pecora, Tim (Sandy) Studier, Angie (Nick) Olson, Dan (Cathy) Studier, Lori (Al) Heeren, and Jill (Paul) Hagen; brother-in-law Brent Buchanan, and many nieces and nephews.

Randy was preceded in death by his father Rudolph; and sister Nicola Buchanan.

Memorials are preferred to the ALS Support Group of NW Wisconsin, PO Box 690, Eau Claire, WI 54702 or St. Joe's Hospice, c/o Jenny Gullicksrud, 2661 Cty Hwy I, Chippewa Falls, WI 54729.

## Susan Studier

CONDOLENCES: (These are in their original, unedited form)

Posted by: Laurie Hennen

Thu October 27, 2011

Sue, Chris, Jason, Josh & Chad .... My deepest sympathy for your loss. Randy will be missed. My thoughts and prayers are with you.

Posted by: Kari Ann Nelson

Thu October 27, 2011

Dear Studier family,

Please accept my deepest sympathy. I only knew Randy for a short time, but got to know that he had a great personality and was a nice person. I feel very blessed to have had the opportunity to get to know him. Your entire family is in my thoughts. Please take care,

Kari Ann Nelson

Posted by: Roland Breunig

Thu October 27, 2011

Josh, Brooke and Randy's entire family: Know that you have a large network of co-workers and friends that share in your sorrow. We offer our thoughts and prayers and wish you peace.

Posted by: Jere Wujcik

Thu October 27, 2011

My deepest thoughts and prayers are with all of you during this most difficult time. Randy was a great boss to me for over 8 years and more importantly he was a great friend. He touched the lives of so many people that I know he will be missed. The one thing that I know for sure about Randy is that he loved his family more than anything, loved his music and he loved the outdoors during hunting and fishing season. Please know that Randy may be gone, but he will never be forgotten. May God's Peace be with you all!

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Jere Wujcik

Posted by: Kelly Swartos-St. Joe's Hospice

Thu October 27, 2011

Dear Studier Family,

My thoughts and prayers are with all of you at this time. It was an absolute honor to know Randy and to be a part of his care team. He was a true inspiration and will never be forgotten.

Posted by: Joel Williams and Family

Thu October 27, 2011

Dear Studier Family,

Our deepest sympathies for your loss. I would like to add one of my memories: I can picture clear as day when my dad and Randy would be up late at night, talking and joking (w/an occasional beer) during our family reunions. Randy will truly be missed by many. We will keep you in our prayers.

Love, Joel

Posted by: Pat Dahl

Thu October 27, 2011

So many memories have been created in the 43 years that Randy was in my life. He was truly an amazing person, brilliant, funny, and so likeable. My heartfelt sympathy to my sister, Sue, nephews Chris, Jason, Josh and Chad and to Janine, Holly and Brooke and to Randy's beautiful grandchildren! He will be deeply missed! God be with you!

Love, Pat

## Susan Studier

Posted by: Linda and John Galkin

Thu October 27, 2011

Dear Studier Family,

Randy was an amazing person and an inspiration to us. In spite of the fact that he was in terrible pain, he was always smiling, laughing, and cracking jokes. Randy was a man of many talents. Our deepest sympathy to my sister, Sue, our nephews and their wives, Chris and Janine, Jason and Holly, Josh and Brooke, and Chad and their children. Randy left many memories for all of us to cherish. We will miss him dearly.

Posted by: mark mueller

Fri October 28, 2011

Dear Sue, Sons and family

My deepest sympathies for such a great loss in your life. Randy was such an exceptional person and I know that I can't fully understand how much he will be missed in the family. I valued and appreciated Randys friendship immensely. His intellect, humor and loyalty has been such an inspiration to me. They way he faced adversity in his last years with such courage, humor and humility is truly staggering and unbelievable. He is a bigger than life person to me. I feel so blessed to have known Randy and the Studier family. and of course it goes without saying, it was wonderful to see that Randy got true religion when he moved to Wisconsin and became a Packer fan.

mark mueller

Posted by: Nathan Staehling

Fri October 28, 2011

My deepest sympathies to the Studier family. Randy will be missed.

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Posted by: Shari staehling

Fri October 28, 2011

I thank God for the gift of Randy's life. What a gift he has been to our family. Being doubly related was very special especially those days we spent so many Sunday afternoons together. God be with you and also in the difficult days ahead. Love you, Sue, Chris, Jason, Josh, Chad and families.

Posted by: Phil Staehling

Fri October 28, 2011

Randy, my cousin brother in law, was a blessing in my life. We had many great times together. Randy had such a great sense of humor and was so much fun. We were life long friends. I will miss him. God be with you Sue Chris Jason Josh Chad and families.

Posted by: Helen Chen

Sat October 29, 2011

Dear Sue and Family,

The first time I met Randy he was fixing dinner (for himself -- Sue and I were going out). As a shy person, I always had problems carrying a conversation, especially with someone I didn't know. On that particular day, I also felt guilty for taking Sue away, which made it more difficult for me to say a word. But Randy made me feel comfortable and welcome. I remember feeling relieved and appreciated his understanding and thoughtfulness. He will be missed.

Helen Chen

## Susan Studier

Posted by: Ruth (Staebling) and Darrell Schlange

Sun October 30, 2011

Deepest sympathy to Sue and family and the entire Studier family. Sorry I didn't have the opportunity to get to know my cousin Randy better. It sounds like he made the most of life and handled his cruel disease with dignity inspired by a strong faith. May God's peace and love and special memories of Randy help sustain you through this difficult time.

Posted by: Ivy Scholfield (Stanley Peterson Family)

Mon October 31, 2011

I just wanted to tell you that our family is thinking of your family today and always. We had the privilege of getting to know Randy at the ALS support group meetings and will not forget how kind, friendly, and intelligent he was and how much strength and determination he had. My dad, Stanley, truly admired him and enjoyed chatting with him at meetings. We were very blessed to have Randy (and family) be part of the group and thankful and appreciative of his support when we lost our dad to ALS last November. I still remember when I asked if I could have a picture taken with Randy and the family at the last ALS walk. They did not hesitate to say yes, and I felt it was quite the privilege. I will treasure that picture always....what a wonderful man and a wonderful family.

Thanks for inspiring us, Randy, and for demonstrating such strength and perseverance. Thinking of you always....

Posted by: Mike Schultz

Mon October 31, 2011

My condolences to Chris and the entire Studier family, I was saddened and shock to read about his passing. It's been a long time since I've seen Randy, probably back in my freshman year in college, but I remember him being a caring, understanding and

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supporting father. I'm sure he's in a much better place in this world.

Posted by: David Staehling

Tue November 01, 2011

My condolences to Sue, Chris, Jason, Josh, & Chad. Early in the year I learned that Randy was thinking of visiting us at our Ozark farm. His health deteriorated too fast so that didn't work out, but he dropped me a short Email back in mid February and we had some very interesting exchanges for a couple of weeks. We talked about our kids and grandkids and I was pleasantly surprised to learn that all of his four sons had graduated from college and pursued good careers. That is something that the whole family can be very proud of. I also found out from his Emails that Randy was quite literate and from his ALS TV appearances also quite good at public speaking. Engineers are generally not known for these abilities.

Posted by: Gretchen Studier

Wed November 02, 2011

Randy,

I never got to spend as much time with you as I wanted. As kids we were so close. I couldn't wait for summer to come so that my family would be going back to MN from GA and I would see you again. I would call your house and then meet you half way with a big hug. We had these all day Monopoly marathons and days where we just hung out together. I remember one fall day in particular. We got into a big pile of leaves and pretended it was a giant nest. We laid there and looked at the clouds and told each other what we saw; elephants, cows, balloons and whatever. And then we went to school together and were in the band together. Mr Waldheim terrified me! Music is a big part of my life too. I always hoped that we would see each other more often as adults, but distance kept us apart. It didn't change how I felt about you and the little place I

## Susan Studier

always kept for you in my heart. I'm so sorry you had to go thru all that you did in the last two years. I miss you. Hugs Gretchen

Posted by: Carol Williams

Fri November 04, 2011

To the Studier Families,

I have known Randy since we were in high school. When he married my sister, Sue, and joined the Schmidt family, I gradually got to know him better. Randy was a very friendly, loving, caring and intelligent person. He had many talents and he especially loved music and playing his trumpet. Since Randy was diagnosed with the ALS disease, some of my siblings would visit and see what we could do to help out with Sue and Randy. Those were the times that Randy wanted to play games. He especially enjoyed playing the card game called 99. He loved to see me lose FIRST in that game, which seemed to happen often. What a teaser! He had a good sense of humor. I can't imagine the pain and difficulty he was going through and yet he enjoyed playing games during the time he had ALS. My deepest sympathy to all the Studier families - Sue, Chris, Jason, Josh, Chad, grandchildren, siblings and spouses, Anne, nieces and nephews. He will be missed and I rejoice that he is now in Heaven singing along with the Angels.

Love, Carol

Posted by: Chad

Mon November 07, 2011

Dad,

Through all the good, bad, and ugly we experienced these past couple years. I would never trade them for anything. I never minded your needs, and always put them first (though I may not have smiled through all of them). It was an honor to be your caretaker. What I am most proud of is the way you handled this disease like a man. You never lost your sense of humor. I clearly

## HEADING HOME

remember details during the last day of your life, and I will never forget the morning of your death. As hard as it was making sure you had passed, I was up to the task. Though I will never forget the look on your face that morning, I am sure you were telling us you found peace. Yesterday I was in a store trying to decide on a product and thought I could call you for advice, then reality hit & I broke down. Again, it was an honor getting to know you better and being there for you as much as I possibly could. I will be here for mom as much as I can. I will miss you dearly.

Chad

Posted by: Ken Kelly Jr.

Mon November 07, 2011

May we offer our condolences to the Studier Families, in your time of sorrow. We pray for you and Randys soul. Although we were not close, our paths crossed briefly in our childhood, since Randy and I were double second cousins. Randy was six (6) years my junior however and we lived in different communities. May the Lord be with Randy and you, his family members, as you deal with your loss. We know that he will be greatly missed. In Gods Name,

Ken Kelly Jr. (Ken and Elnora Mueller Kelly [Carl and Sophie Studier Mueller]).

Posted by: Marcella Sodman Johnson

Wed November 09, 2011

My condolences in the passing of Randy. Although I had not met Randy, his dad Rudy was my cousin and friend, as is his mother Anne. After reading all the loving messages I feel that knowing him would have been a blessing indeed. May God surround you all with His love, comfort and peace. I have lost my connection with Anne since her remarriage and would like to re-connect with her. Sincerely, Marcella Sodman Johnson

Susan Studier



*John and Linda Galkin, Carol Williams, Kenny Schmidt, Phil and Shari Staebling, Randy and Sue, Pat and Rick Dahl, Luverne and Darlene Hauge. They came for a visit in January 2011. Once that weekend I was transferring Randy with the sit-to-stand pivot when his knees buckled. Rick, Pat, and John were nearby and had to grab Randy and put him on the lift-recliner.*

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*By mid-June, 2011, Randy's right hand was useless. He frequently asked me to gently uncurl his fingers, as it was uncomfortable for him.*



*Randy was happy to see old friends, John and Patti Hareid and Marv and Dianna Bednar.*

SUE'S JOURNAL ENTRY THE MONDAY AFTER THE FUNERAL

MONDAY, OCT. 31, 2011: I tried to get into the paperwork business that needs to be done, but couldn't, so I went downstairs and got Randy's "blankie" and took a nap. Then I went out to the garden to see if I could salvage any carrots or beets. We have had temperatures in the 30s in the nights. As I approached the garden I noticed the butter lettuce - 2 rows of tall withered, dead stalks. And then I saw one - only one - perfectly green, healthy head of butter lettuce. My immediate thought was that was God's assurance to me that Randy's ALS-battered and withered body has been made perfect in Heaven. Amen.



*This was one of Randy's last acts of independence. He hadn't been walking for several months prior to this, but his hands and arms were still functional. Chris insisted that we get him onto the 4-wheeler. It wasn't easy, but Randy enjoyed riding around Chris's property.*

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*Our last family photo with Randy, early September of 2011, approximately 7 weeks before he died.*



*The 1<sup>st</sup> Annual Randy Studier Memorial Hockey Tournament, Thanksgiving Day, 2013. Names are on the following page.*

## Susan Studier

*Lying on the ice with the white helmet is Niko; with red jersey is Leo, and the goaltender is Noah.*

*With the gold helmets, L-R is Sebastian, Elias and Anna.*

*With the white helmet and gold jersey is Paul.*

*Kneeling to Paul's left is Brittany.*

*Gray jersey on far left is Brooke.*

*Red jersey, standing, is Josh, and in front of him is Gus.*

*Standing behind Josh are Ellie and Jason.*

*The standing goalie is Gabe.*

*And wearing no helmet is Chris.*



*Randy, acting like a nerd in 1967. He was an electrical engineering student at GMI (now Kettering University) in Flint, MI.*



NOTE FROM THE AUTHOR

My hope is that my readers will think about what happens after death and will decide to follow Jesus now rather than wait until they are on their deathbed. I have hope in Randy's deathbed confession based on the Biblical account of the thief crucified alongside Jesus in Luke 23:40-43. But, I believe it is better for each of us to not rely on an end-of-life saving grace, but to believe and obey now.

Here are the Bible teachings I value most:

Luke 10:25-28

<sup>25</sup> On one occasion an expert in the law stood up to test Jesus. "Teacher," he asked, "what must I do to inherit eternal life?"

<sup>26</sup> "What is written in the Law?" he replied. "How do you read it?"

<sup>27</sup> He answered, "Love the Lord your God with all your heart and with all your soul and with all your strength and with all your mind"; and, 'Love your neighbor as yourself.'"

<sup>28</sup> "You have answered correctly," Jesus replied. "Do this and you will live."

Matthew 10:32-33

32: Therefore everyone who confesses Me before men, I will also confess him before My Father who is in heaven. 33: But whoever denies Me before men, I will also deny him before My Father who is in heaven.

Luke 15:10:

"In the same way, I tell you, there is rejoicing in the presence of the angels of God over one sinner who repents."

Romans 10:9:

If you declare with your mouth, "Jesus is Lord," and believe in your heart that God raised him from the dead, you will be saved.

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Matthew 28:16-20: The Great Commission:

<sup>16</sup>Then the eleven disciples went to Galilee, to the mountain where Jesus had told them to go.<sup>17</sup> When they saw him, they worshiped him; but some doubted. <sup>18</sup>Then Jesus came to them and said, “All authority in heaven and on earth has been given to me. <sup>19</sup>Therefore go and make disciples of all nations, baptizing them in the name of the Father and of the Son and of the Holy Spirit, <sup>20</sup>and teaching them to obey everything I have commanded you. And surely I am with you always, to the very end of the age.”

## ABOUT THE AUTHOR

Susan J. Studier was born and raised on a farm in south-central Minnesota, three miles from her high school sweetheart, Randy. She and Randy married young and spent 43 years together, raised 4 sons, and lived in 7 different cities: Flint, MI, Sterling Heights, MI, Glenville, MN, Albert Lea, MN, Chisholm, MN, Eveleth, MN, Stewartville, MN, and Eau Claire, WI. Susan spent most of her working life as a family law paralegal. Susan misses Randy's love and humor every day of her life.