

Beyond The Red Door



## LIFE, LOVE, FAITH & ALS

By E. Ray Walker

Brad Hansen believes in miracles. He could use one.

Brad has amyotrophic lateral sclerosis (ALS, or Lou Gehrig's disease), a neurodegenerative disease that affects nerve cells in the brain and spinal cord. The cause is unknown. The disease weakens muscles and affects physical function. The main symptom is muscle weakness. Medication and therapy can slow ALS and reduce discomfort, but there's no cure. ALS is fatal.

Miracles? "I do believe in miracles. I believe God's power is infinite," Brad says. "If I were to wake up tomorrow and find that God has bestowed a miracle on me. I'd know exactly where that miracle came from." He adds: "I won't ask for one. God has this. One blessing with ALS is having a 'long goodbye.'"

### HOW IT BEGAN (Brad's posting on an ALS website)

*I will never forget the actions of the ALS team that day. They were comforting and compassionate.*

*It started with left-hand weakness and difficulty in grip strength. As a lifelong athlete, I dismissed it as being out of shape or age-related. This progressed from January 2022 through the spring. I visited the (primary care physician) in April, he referred me to a spinal specialist, who did many tests including blood, X-rays and MRIs. While everything came back normal, he referred me to a hand surgeon.*

*By July 2022, my left wrist/hand finally stopped working. We were getting ready for a tendon transfer surgery when I developed foot drop (a symptom that occurs when the calf muscle and Achilles tendon tighten, pulling the heel up and causing the front of the foot to drop) in my left foot. By the time I made it to the pre-surgery visit, the hand surgeon stated that he couldn't do surgery because none of the tendons or muscles even worked in the wrist. It was obvious that something bigger was in the background. Both the primary care physician and the hand surgeon were able to get me in to see the Neuromuscular/ALS team at the University of Virginia hospital.*

*This appointment was on my birthday, so it was supposed to be a happy day. My son had planned a birthday picnic for lunch.*

*We met with the UVa. team in the morning. After clinical testing of reflex and walking, they scheduled electromyography later that afternoon.*

*After a wonderful birthday lunch, I did testing in the afternoon. I will never forget the actions of the ALS team that day. They were comforting and compassionate. Three doctors pulled up chairs and sat with us. They confirmed that I did indeed have ALS. My wife and I were devastated. The doctors cried with us and were supportive. They spent hours with us, which seems incredible these days.*

*What a gut punch! ...*

*This is a beast of a disease but I have a tremendous community holding me up, and I feel blessed.*

## **PASSING THE PEACE, AN ANGEL, AND A NO-SWEAT WEDDING**

Bradley Hansen met Lydia Brown in church when both were graduate students at Mississippi State University in Starkville. Both are lifelong Episcopalians, he from the Maryland suburbs of D.C., she from picturesque Winona, Miss. Brad was working on his master's degree in oenology (winemaking) after earning a bachelor's degree in botany from Marshall University in West Virginia. Lydia was working on her master's in clinical psychology.

*(Picture right: The newlyweds leave the Episcopal Cathedral in Jackson, Miss., after their wedding on Jan. 20, 1990.)*

At first, they sat near — but not next to — each other in church. For several weeks their only interaction was the passing the peace during the service.

Brad: "Peace be with you."

Lydia: "And also with you."

Warm sentiments, certainly, but hardly romantic.

After a few weeks, Brad finally found the courage to talk to Lydia.

Brad's first impression of Lydia: "I thought I'd found an angel."

Lydia's first impression of Brad: "I only saw his shoes at church. He wore these Hush Puppies that I could tell he only wore on Sunday because the edges of the rubber part of the Hush Puppy had red



carpet (fibers) because, it seems, most Episcopal churches have red carpet. I would only look at his shoes when we were passing the peace, and that's about as far as I got."

They dated for 3/12 years before getting married. But first, let's talk about Brad's proposal. "I picked out the ring, and I'd talked to my parents. Old school — I invited her father to lunch at a sandwich shop in Lydia's hometown and asked for his permission to propose to Lydia. He pretty much knew what we were going to talk about. He gave me a little bit of a hard time. As I understand it after the fact, it was all in good fun."

For the actual proposal: "I had it all planned out. We were going to meet around noon in the center of campus near the chapel. ... It was getting romantic. We were in the middle of the garden. About the time I got to my knee to pop—

*DAH! DAH! DAH-dah-da-dahhh! DAH-dah-da-dah-da-da-dahhh.*

A marching band came by, blasting brass, percussion and woodwind music far and wide across the Mississippi State campus. Brad: "So I had to wait until they passed to ask the question. I tried to make out that I actually paid the marching band."

Lydia: "It was perfect timing. I knew he couldn't have paid the band."

Just moments after Brad's proposal, Lydia's phone rang. Her dad: "All right Lydia. I gotta ask — I gave him permission, but what do you think? I can take it back."



There was no need to take anything back. She said YES.

The wedding was at the gothic-revival St. Andrew's Episcopal Cathedral in Jackson, Miss., on January 20, 1990. Lydia notes that it is "the only time you can get married in Mississippi without sweating."

The ceremony was very formal, and beautiful, Lydia says. Only white flowers could be used. A slow, steady rain added to the romantic ambiance.

Brad: "I didn't go down there (to Mississippi) thinking about finding a wife. God put us in the right place at the right time."

Lydia: "God brought us together." And, "The church was the perfect place to meet."

*(Pictured left: The Hansens leave their wedding reception)*

One month after the wedding, the newlyweds moved to Georgia, where Brad had accepted a position at Chateau Elan Winery. After 10 highly successful years and 250 awards there, Brad and Lydia relocated to Virginia, where Brad brought his award-winning talents to Prince Michel Winery near Madison. Lydia was the director of human relations at Prince Michel. They were there for 25 years.

Brad and Lydia have two adult children, Christian and Rhys.

## ALS GOES IN ONLY ONE DIRECTION

Since the initial ALS diagnosis in 2022, there has been a steady progression for Brad, who turns 62 in October. “It goes in only one direction,” Brad says. From bad to worse to, eventually, undeniably horrible.

When Brad wrote about the beginning of this ordeal for the ALS website, “My left hand was pretty much gone. I was still walking, using a cane or a walking stick. In the spring after diagnosis, I started noticing my lung capacity becoming involved. I need to use a ventilator at night. Sometimes in the day, depending on activity.”

Since then, he says, “the weakness, the weariness, exhaustion ... those progressed to the point where I could not walk anymore.” It was devastating news for a former elite high school and college track athlete.

Recently, his right hand has shown weakness. It’s still working. “It’s my dominant hand.” His shoulder muscles are deteriorating.

If — and that’s a big “if” — if there is anything good that can be said about ALS, it’s that it is a generally painless disease.

*(Pictured right: Brad and Lydia at a crab fest in Victoria, British Columbia.)*



With a powered chair, Brad can get around the house. With Lydia’s help, he can stand and take a step. “But primarily I’m in the chair 100 percent of the time.”

Can you grip a fork or a spoon to eat? “I can still use those. Lydia does the cutting.”

He still has his taste, smell, hearing, sight and cognitive abilities that do not diminish as the disease progresses.



The expense of Brad’s care is hard to calculate. Brad: “I think we are blessed. It hasn’t been as expensive as I thought it was going to be at this stage. Having said that, it is going to get very expensive as time goes on. ... We won’t know what I’ll need in six months, or six years.”

Lydia, whose years as a human resources director and who comes from a family with insurance business backgrounds, is experienced in dealing with companies sluggish in paying up. “I can be persistent and never take no for an answer.”

Despite the physical setbacks, Brad is still the master chef at home. “He cooks every day. He is not a one-pot guy,” Lydia says. “I can always tell how good this meal is going to be by how many dishwasher loads he goes through — two, it’s going to be fabulous; three, it’s going to be just out of this world.”

*(Pictured left: Brad with his sister, Lisa.)*

## 'WHY ME?,' NO 'WHY NOT ME?'

Brad easily qualifies for the Good Man Hall of Fame. A loving and devoted husband and father, a devout Christian, a hard worker, a generous and kind man. And then, in the prime of life, he is struck by a brutal illness whose cause is unknown. He could be forgiven if he questioned his faith in a loving, benevolent God.

Brad: "I've always had a very strong faith. I have not been one that questions God. I also understand that it's a journey that we are all on. This disease isn't just happening to me. In a way, it's happening to both of us."

Lydia agrees: "We both have ALS."

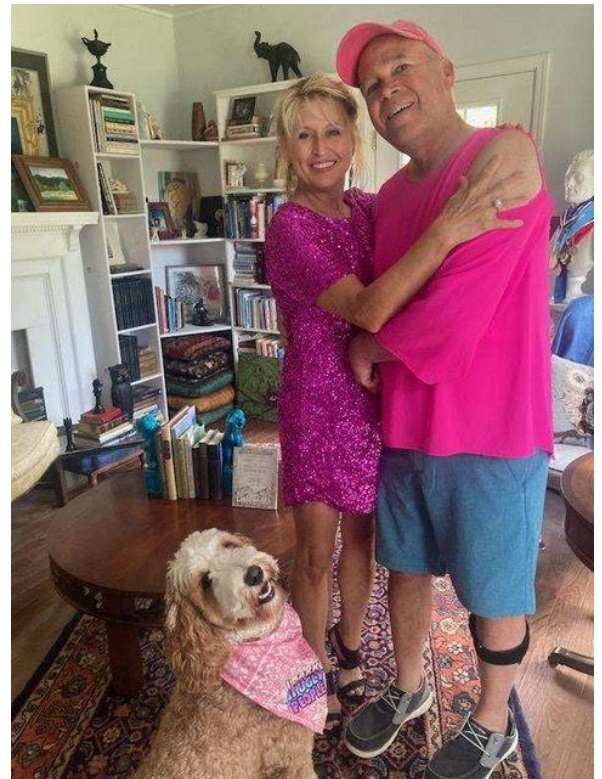
Brad: "I know that Lydia is looking at it from a different perspective because (she's) the caretaker."

"My faith in God, I think it's only gotten stronger. Maybe I realize more poignantly the blessings that abound that maybe I took for granted before. And I look at (Lydia) and the kids, and that's really all that makes my day. I don't need work, especially full-time work. I try not to let that define me."

Do you ever ask, "Why me, Lord?"

Brad: "Certainly I don't because I'm also reminded that there are people much worse off than me. Why not me? It is what it is — in the sense that it is a disease that takes five- to six thousand people a year."

"It is fairly rare, but if I asked that question, the answer becomes, 'why not you?' I don't feel like God is punishing me."



*(All dressed up to see the movie "Barbie.")*

Some people who have experienced a life-changing trauma can see bright spots from the experience. Because of a shared experience, they feel closer to a spouse. Perhaps even a strengthened love for another and a strengthened faith in God. Some become a better person because of the experience. Others say they recognize positive characteristics in others they may not have fully appreciated before. Does any of this resonate with you?

Brad: "Yeah, I would say that a positive would be the understanding that we have a very limited timeframe on this side of heaven, and really make sure we live this moment. To tell each other that we love each other, and that we mean it. And we show our children this understanding and grace that God has blessed us with."

Lydia adds: "I think (Brad) has always been that positive kind of person, which is so nice. Every day has been like a new, happy adventure. And I love that about him."

Looking ahead, if there is no miracle cure soon, are they prepared for what's next?

Brad: "I am. I'm not hastening it along. I'm not in a place where I wish this whole thing would hurry up, and I hope that I never get to that place. Even in this, I'm still excited to see what the day holds; still

excited to see what Lydia wants to do. I think that's one of the secrets to happiness ... to always find joy."



*(Brad's high school sponsored a fundraiser for a track scholarship.)*

## A JOURNEY FOR GODLY PURPOSES

Lydia has written, "Brad and I agree that we are on this journey for Godly purposes." What do you mean by that?

Lydia: "We're on this path; it is a journey. It is an odyssey. I feel like this whole thing happened for a reason. I feel like we were given this horrible diagnosis to help spread the Gospel. And that is our job as Christians; to glorify God and, hopefully, spread the message. I'm not going to just weep and cry and get angry. I'm going to work this for God."

Once a month the family goes to a therapist and talks things out. This will be crucial as Brad enters later stages.



Lydia: "I have moments. The thought of not having Brad is devastating, and every moment I have him here, I'm OK, regardless. I pray hard all the time, and I know that God absolutely has this."

The Hansens proudly acknowledge they have been blessed by a very supportive community. Among those blessings:

—The Madison community, on its annual Madison Day, came together to build a ramp for Brad's access to and from the house on his powered chair.

—An incredibly generous and supportive family in Culpeper donated the powered chair to Brad. And when's he's done with it, "I'll donate it to the next person." This family, who lost their husband/father/grandfather to ALS, meets with the Hansens regularly to give support, comforting words and advice.

*(Pictured left: Brad with his high school track coach and members of his team. They still hold state records in Maryland.)*

—The Madison contractor who heard their story. He showed up at their house and promised to remodel rooms for better access. He is supplying time, talent and many materials at a ridiculously reduced rate because he was moved by God’s calling and wants to share his faith through his talents.

—Supportive friends and neighbors. Says Lydia, “It is difficult for people in the community to know what to say. I want people to know we understand that. We just don’t want them to ignore us because they don’t know what to say. ... I want people to talk to us.”

It’s rare that a day goes by when the Hansens don’t get a visit or a call from someone touching base. “I was told early on that we would see the best and the worst of humanity. That is proven true every day, but we focus on the best parts,” Lydia says. “One of the hardest parts of this journey has been reconciling the loss of our jobs. Regardless of that hurt, we now get to spend our energy focusing our time with each other and all our amazing family and friends both old and new.”



### More blessings:

—ALS Association. “The ALS Association is phenomenal,” Lydia says. It has donated equipment, and it will provide a lift for assisting Brad when the need arises. The association also calls just to check in. Team Gleason, founded by the legendary New Orleans Saints football player Steve Gleason, who has ALS, and his wife, has helped with equipment and voice banking.

—UVa. ALS team. Lydia: “This group of amazing professionals has honestly made such a difference in keeping us positive and proactive in fighting ALS. They are our family now. We believe much of Brad’s success and slow progression is due to their frequent oversight and care.”

### ADVICE FOR OTHERS

This has been a difficult journey for both. What they have learned will benefit others who find themselves in a similar situation:

From Brad: “First and foremost, lean into your faith. This is one of those situations where you can’t go it alone. No matter how tough things will become — and they will become very tough — we will be taken care of.”

“Stay up with your doctor appointments. If you have something kind of strange that you cannot figure out, see the doctor.” (Remember, Brad’s ALS diagnosis began with a casual mention to his doctor about a weakness in his left hand.) “This is a kind of disease where it is better to mitigate early than try to play catchup at the end.”

From Lydia: “You have to advocate. You have to push hard with the (medical) community. Push it. Advocate once you get the diagnosis.

Don’t take no for an answer. Escalate to supervisors. If you have a voice, speak up for the people who don’t feel that they can express themselves very well. If you’re helping one person, you’re helping more. Let your faith shine. Absolutely, this is what people need to see. Sucky things happen, but that doesn’t mean you lose your love, your joy, your humanity. I can’t say that enough.”



## A LOVE COMMUNITY

As longtime members of St. Stephen's Episcopal Church and involved in many of its activities, how has the church helped during this difficult time?

Lydia: "Just knowing that they are there, that is so important to know that I have a faith community. They may not be able to come and help knock down a wall or pay for Brad's ventilator bill, but having that support is tremendous. I have always felt with St. Stephen's, more so lately — I think it kinda started with Ben (former rector Ben Shelton) and has really ramped up with Trent (current rector Trent Moore) there is a love community there. I don't know if it's the vibe or what, but I just feel good when I'm there. I feel like if I stood up at any time during the service — before, after or during — and said I need a hug, I think I'd get it in a heartbeat. I feel good knowing that they are there."



*(The Hansens on a trip to Canada in fall, 2024.)*

"We also have a very strong community with Piedmont Episcopal in Madison. They had a really strong youth program when our kids were growing up. I get cards and phone calls from them just checking on how we're doing. It doesn't have to be physical or financial. That's what I'm so happy about."

"I want our whole community to get involved with the Americans with Disabilities Act. That would be a great mission."

"As a healthcare administrator in Georgia and a human resource director in Virginia, I never knew I would personally rely so heavily on all aspects of the ADA. From navigating thresholds around town to speaking out against workplace discrimination and lack of adaptive equipment, we can all make a difference in so many ways. Just look around you and see how you can make it easier for someone who needs that support."

"We are so blessed, and I say that without any reservation. ... The common thread is love, joy and faith the whole way through; and that's where we're still going. Every day is new."

A miracle. One of many.

## **GIVING A HELPING HAND**

The Hansens have been blessed in ways too numerous to list. Unfortunately, ALS is a devastating disease financially. Looking ahead, there is a pressing need for a wheelchair van for Brad.

To help finance that van, St. Stephen's will host a fundraiser dinner on Friday, March 21, from 6 p.m. to 9 p.m. It will be in the Parish Hall. The dinner will be a coursed event with wine pairings.

In addition, there will also be an online auction, sponsorships and donations. Links to the online auction will be available through the St. Stephen's website and other media platforms in early February with bidding ending March 21.

To sign up to attend this dinner, please notify the church office at 540-825-8786 or via email at [ssec@ststephensculpeper.net](mailto:ssec@ststephensculpeper.net).



*(Ash Wednesday at St. Stephen's.)*