**I’m Still Your Coach, Washington Post, August 19, 2022**

Alone at his kitchen table, Patrick Behan opened the online meeting he had called the day before, short notice meant to limit gossip and worry. He stared into his laptop screen at faces he considered family.

Behan saw the players and parents of the boys’ basketball team at St. John’s College High, where he had been the coach for the past five seasons. As introduction, he detailed the start-of-school schedule. He informed incoming players their fall workouts would be taxing. Maybe the mundane would settle his nerves.

“The main reason I wanted to meet is to share some personal news about myself,” Behan told them. “I’ve known about this, and, um, I hate to get emotional, but I figured that this would … Sorry.”

He leaned back and sipped from a red water bottle. He cleared his throat, trying to find the words.

“Late spring, early summer, um … ”

He blinked and rubbed his nose, his breath catching.

“I haven’t cried like this since Malik made the game-winning basket against Gonzaga.”

He chuckled and cleared his throat.

“I was diagnosed with ALS.”

In early May, doctors told Behan he had amyotrophic lateral sclerosis, the terminal neurological disease commonly associated with Lou Gehrig and [the Ice Bucket Challenge](https://www.washingtonpost.com/news/to-your-health/wp/2015/08/19/scientists-are-crediting-the-ice-bucket-challenge-for-breakthroughs-in-research/?itid=lk_inline_manual_11). It has no cure, causes harrowing muscle degeneration and carries an average life expectancy of three to five years after diagnosis. The best treatments are emerging drugs, promising but not proved. It has ravaged Behan’s family, and it came for him at 34 years old. Only 3 percent of ALS patients are so young.

Behan, a6-foot-8 former power forward at Bucknell, cannot lift his left arm higher than 90 degrees or wiggle the toes on his right foot. He walks with a hitch. Unopened medical bills stack up on a table by his front door. A pill case sits on his footrest. He doesn’t know how or whether his body will change, and he tries not to think about it.

“Unfortunately, you’ll learn more about the disease,” Behan told his players, tears rolling down his face. “It’s a vicious thing. There’s been significant progress in terms of what it is, what can be done. While you’re seeing me like this right now, I’m still your coach. And you still have everything humanly possible that I can give.”

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Basketball season had been three months of bus rides, fast food and constant stress. When it ended last spring, Behan resolved to get back in shape. One night in early March, he dropped to his floor for a set of push-ups. He struggled to complete the first and couldn’t finish the second, his left arm and shoulder too weak to lift his body. At night in bed, his girlfriend, Nataly Johanson, noticed Behan’s upper arm muscles twitching. He knew something was wrong.

Johanson guessed the symptoms might be related to stress but insisted Behan see a doctor just in case. An MRI exam indicated it could be a pinched nerve. Another test determined it wasn’t. Behan told Johanson he feared it was ALS.

In late winter 2020, Behan’s father, Jeremiah, started feeling weakness and stumbled when he tried to walk. His muscles deteriorated rapidly as doctors struggled to determine a cause. By the time he was diagnosed with ALS, it was too late for treatment. That April, Jeremiah died at 70.

Behan’s best friends did not know about his family’s ALS history until Jeremiah died. Behan’s grandmother died young of ALS. His aunt died at 30, and his uncle died of ALS. By his sister Alexis’s count, nearly 10 Behans have had ALS.

Doctors diagnose ALS as a last resort, and over weeks Behan endured a battery of tests. None eliminated ALS. In early May, he underwent an electromyography at a neurologist’s office, a test that would determine whether he had a motor neuron disease. It wouldn’t be a finaldiagnosis but a near-certain signal of ALS.

The doctor walked in the door with results two hours later. Behan could tell by the look on his face what he was going to say. He cried in his car and called his sister and girlfriend.

On May 6, a doctor gave him the final diagnosis. Sitting in the office, he turned to Johanson. “I don’t care what it takes,” Behan said. “I want to fight this however possible.”

“After you hear that diagnosis, anything that was normal is not normal anymore,” Johanson said. “You always need something to give you purpose. In his case, it was fighting it.”

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Behan's father died of ALS; his mother was diagnosed with lung cancer in 2020. (Caitlin Buckley for The Washington Post)

Behan would have many tough conversations, none tougher than the one that weekend with his mother. Darcy Behan was diagnosed in late 2020 with Stage 4 lung cancer. Behan drove 90 minutes to her house in Easton, Md. He told his mother her strength would give him courage in his own fight. “We’re both going to fight,” Behan told Darcy. “You’re fighting. I’m fighting. We’re in this together.”

Behan called his friend Pete Thamel, an ESPN college sports reporter whom Behan met while playing at Bucknell. Thamel had a connection at Boston College to Nancy Frates. She is the mother of Pete Frates, the former BC baseball player whose promotion of the Ice Bucket Challenge [helped raise $100 million for ALS research](https://www.washingtonpost.com/local/obituaries/pete-frates-whose-battle-with-als-helped-popularize-ice-bucket-challenge-dies-at-34/2019/12/09/5c76f584-1abb-11ea-87f7-f2e91143c60d_story.html?itid=lk_inline_manual_27) before he died in 2019. She has seen what ALS does, and she has made it her life’s mission to help people afflicted with it.

The next afternoon, Behan and Johanson were on a Zoom call with Frates. The first thing she told them was, “Open up your heart and open up your arms for all the love that is going to come to you.” She asked questions and gave counsel about creating a support group that would allow Behan to focus on living his life and fighting the disease.

Frates emailed four leading ALS doctors and researchers. Within hours, they all emailed back. Behan would be enrolled at the Sean M. Healey and AMG Center for ALS at Massachusetts General Hospital in Boston, the top ALS treatment facility in the world, under the care of James Berry, a leading ALS doctor.

With Frates’s guidance, Behan developed a plan. Alexis and Anthony Sosnoskie, his best friend from high school, contacted a lawyer to create a trust. Tim Brooks, a coaching friend, helped organize a fundraising cornhole tournament and college football viewing party Sept. 17 in Olney. A [web site rolled out this month](https://www.behanstrong.com/) under the banner Behan Strong, with the hashtag #PunchBack4Pat.

Behan met Ron Hoffman, a caregiver who runs the nonprofit Compassionate Care ALS and provided mental and spiritual support. Behan contacted Chris Caputo, the new coach at George Washington, who had recruited Behan as a young George Mason assistant. Caputo helped Behan arrange appointments at George Washington University Hospital. Behan spoke with Blair Casey, the ALS caregiver for former New Orleans Saints player Steve Gleason, who advised him to avoid Googling for medical guidance.

“It could have been easy for him to collapse in on himself,” Alexis said. “Instead, he tried to expand his network.”

Genetic testing revealed Behan had the SOD1 gene, a sliver of good fortune buried under a sea of bad. Researchers have developed a drug called Tofersen that treats SOD1, a form of the disease only 2 percent of ALS patients have. Money raised from the Ice Bucket Challenge [made possible those kind of breakthroughs](https://www.washingtonpost.com/nation/2019/12/09/pete-frates-who-helped-inspire-als-ice-bucket-challenge-dies/?itid=lk_inline_manual_34). Clinical trials have shown reduced muscular and respiratory decline, according to parent company Biogen.

Behan read about Chris Snow, a Calgary Flames assistant general manager who was diagnosed with ALS in 2019 and took part in an early Tofersen trial. Doctors gave Snow less than a year to live. Snow uses a feeding tube, and his right arm has withered. But this spring and summer, Snow [watched the Flames in the playoffs](https://www.nytimes.com/2022/05/03/sports/hockey/chris-snow-calgary-flames-als.html) and ate lobster with his family at Merrymeeting Lake in New Hampshire.

In the first round of calls he made to share his diagnosis, Behan cried. In the next wave, he spoke with confidence. “I’m going to be okay,” he would tell them. “There’s a lot of good that can be done. I’m going to fight this.”

Alexis often reminds her brother that treatments have progressed since their father died. Behan is younger, stronger. ALS presents uniquely, even among people who share genes. “It’s different,” Alexis tells him. “It’s different.”

During one doctor’s visit, Behan spotted a chart on the wall detailing the average life expectancy for different forms of ALS.

“Then I thought back to Steve Gleason, and the doctors told him you’ve got a year to live,” Behan said. “And he’s alive. I’m sure Chris Snow’s doctors told him something [similar], and look where he is. So you see things like that, and you’re like: ‘F--- you. Why is that here?’ ”

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In the overwhelming moments after he received the diagnosis, Behan asked a doctor, “Will I still be able to coach?” As long he was physically capable, he was told, then he should continue doing what he loved.

From youth, Behan devoured sports. He played marathon games of H-O-R-S-E and one-on-one on the cinder block court Jeremiah built in their Leesburg backyard. He memorized rosters and wrote game recaps in a composition notebook. He started a college football blog in high school. On long car rides with Brooks, they passed time reciting old NCAA tournament brackets from memory.

In high school, Behan shot to 6-foot-8 and transferred to Notre Dame Academy, then moved on to Bucknell. “He had skill, he could shoot it, tough as nails,” former Bucknell coach Pat Flannery said. “ … I used the word old soul. If there was a group of them, he was always the guy in the middle of it. You just could count on him. He was just so solid.”

Behan played professionally in Germany for a season, then semipro in the United States as he figured out what came next. He considered sports writing, and Thamel got him freelance work for the New York Times when the 2011 NCAA tournament came to Washington.

Behan covered a second-round game between Pittsburgh and Butler [that ended in chaos](https://archive.nytimes.com/thequad.blogs.nytimes.com/2011/03/19/scenes-from-the-final-seconds-of-butler-pitt/), with Butler winning by a point after consecutive fouls nowhere near the basket. In the locker rooms afterward, he saw Pitt players sobbing and coaches consoled by families. He watched Butler players hug each other and celebrate.

“The joy, the heartbreak — it’s like, ‘That’s where I need to be,’ ” Behan said. “For right or wrong, that’s kind of who I am.”

He spent nights recruiting across Maryland, Washington and Northern Virginia, and in those gyms he fell in love with the high school game. He got a job the next year as an assistant at St. John’s, moved to be the head coach at St. Mary’s Ryken and returned, at age 29, to become the St. John’s coach.

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Friends view Behan and basketball as inseparable, something less a part of his life than a piece of his soul. When he met Johanson four years ago, his offer of a first date was to come watch St. John’s play Bishop O’Connell.

ALS is insidious in a thousand different ways. One is how it makes people feel less like themselves. Behan feels most like himself on a basketball court. The best ALS patients can hope for is maintenance of symptoms, not improvement. “Coaching, that’s the one thing where I actually feel like things improve,” Behan said.

This summer, he coached a dozen St. John’s games and ran basketball camps. When he stood to instruct a player or yell at a referee, he felt intense focus on the moment, his illness fading out of his mind. He told his assistant coaches about his diagnosis but otherwise kept it private.

“Our conversations weren’t about how he was going to handle this awful disease,” assistant coach Patrick O’Connor said. “They were about, how are we going to handle a 1-1-2-1 press? How are we going to handle the other team’s ball screens?”

In the first week of August, Behan met with St. John’s President Jeffrey Mancabelli to share his diagnosis and tell him he planned to coach. Mancabelli heard optimism and faith in his voice and asked how the school could support him. “He’s going to be a model of courage to the students and to everyone around him,” Mancabelli said.

A few nights later, he called the meeting to tell his team.

The Cadets’ first full practice is in early November. Behan knows he will delegate more — no morechoosing designs for team gear. Early in the summer, he could still rebound for players. In July, a 6-year-old basketball camper asked for help tying his shoes. Behan knelt down and lost his balance. He barely mustered the strength to get back to his feet.

Behan doesn’t know what his body will allow him to do. He just knows he will coach.

“My first reaction was what a lucky bunch of kids that get to see this,” Nancy Frates said. “What a lucky, blessed community that they’re going to get to see true heroism, true courage, true selflessness. When you see the impact he’s going to have on this community, it’s going to be like nothing those people have seen. These people will be changed forever.”

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**Finding light in the dark**

On a recent morning, Behan ate a bacon, egg and cheese bagel sandwich in his Alexandria living room, “SportsCenter” on in the background. Doctors tell him to eat as much as he can, and the protein shakes remind of his father’s final days. He swallowed a cocktail of 14 pills; that day he didn’t need a 15th, his anxiety medication.

On a chair rested a breathing device, a plastic pouch of air attached to a crinkled tube meant to maintain lung strength. Behan wedged the air bag under his right armpit and placed a clip on his nose. He exhaled deeply before he stuck the end of the tube in his mouth. He squeezed the bag against his body and inhaled nine times. The air expanded his lungs. He breathed out slowly. He repeated the process.

Behan has felt his body grow weaker. His limp, caused by weakness in his right foot, has become more exaggerated. When he exerts himself, he breathes heavy. He loves pools because the water soothes his muscles and he can stretch without bearing weight. When he flies, he checks his suitcase because he knows he won’t be able to lift it into the overhead.

After he finished breathing exercises, Behan walked outside to his gray truck. He wanted to visit players at a voluntary weightlifting session. As he drove down Rock Creek Parkway to St. John’s, he considered the possibility of buying a new car.

“Will I be able to drive?” Behan said. “The pushback is like, you could say that about coaching. You could say that about anything you do. Don’t try to predict the future. Focus on now.”

Behan hates talk about death, even the use of the word. Something a therapist told him months ago, though, stays with him: “Death is on your left shoulder.”

“Whenever you’re making a decision, go to your left shoulder and ask the question, Is this something that is going to make my life better? Is this something I’m going to enjoy and enhance life?” Behan said. “If the answer is yes, then do it. If you’re still not sure and it’s a coin flip, just make a decision because if you’re thinking about it, you’re just wasting time. If you’re right or wrong, just make a decision.”

Behan pulled into St. John’s parking lot and walked through the athletic center. “What’s up, Coach Behan?” one kid asked. He high-fived and hugged his way to the weight room. Before he entered, he stepped on the scale. “247,” he said. “That’s a good sign.”

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“I’m still your coach,” Behan recently told his team. “And you still have everything humanly possible that I can give.” (Caitlin Buckley for The Washington Post)

He opened the door and saw players squatting barbells. “We got a crew today!” he said. He stayed for a few minutes, chatting with a couple of freshmen, and headed back to his office. He proudly pointed out old media guides on the wall with photos of his players who played in college. He had been standing for about an hour, and his legs felt wobbly. He sat down behind his desk.

Behan finds light in the dark. He caught a Red Sox game at Fenway Park and ate Italian feasts in the North End on his first treatment visit to Boston. He splurges on good food and drink.

Last week, Sosnoskie invited Behan to stay at his brothers-in-law’s in St. Mary’s County for a night. As they drove around, Behan pointed out places he used to visit. At the house, Behan propped an iPad on the pool deck and watched golf from the water. “Good, you’re happy,” Sosnoskie said. He handed Behan a cold beer.

Behan doubts he has the stamina for extravagant vacations, but he still has plans. He wants to take another tripto Maine. The Red Sox will be in town for his next visit to Mass General. He loves Ohio State, a consequence of the buckeye trees that lined streets near the school where his mom taught. Sosnoskie’s brother lives in State College, and he wants to see Ohio State play at Penn State this fall.

“He has a bucket list of things he wants to do without calling it a bucket list,” Sosnoskie said.

One morning this month, Behan sat in his living room, “SportsCenter” muted on the television. A visitor asked Behan what scared him.

“The outcome,” Behan said. “Yeah. And not being able to achieve or do certain things you’ve always wanted to do.”

What are those are things?

“Just, you know,” Behan said. “Sorry.”

Behan wiped his face with a tissue, sipped his water bottle and remained silent for 30 seconds.

“Having a family,” Behan said. “The things that I enjoy doing now, not being able to do them, you know, for more years.”

Reminders are constant. Every bill is a reminder of the horrible illness he has and how much it costs. Every trip could be interrupted by phone tag with a doctor’s office. Every morning means another two handfuls of pills. “I’ve come to accept it,” Behan said.

Behan still FaceTimes his mother every day. Seeing her, he said, is a constant source of strength for him. Alexis recently underwent genetic testing and started the six-week wait for results to find out whether she won or lost a cosmically cruel coin flip.

On Monday afternoon, Behan drove home from St. John’s and parked across the road from his house. He would fly to Boston that evening for three days in a doctor’s office. Sosnoskie and Brooks would meet him there, and he would eat great food and drink through happy hour with two of his best friends. Basketball season was another day closer. He looked over his left shoulder and crossed the street.