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Dementia deals cruel blow to Lee County deputy, 39

Loving husband, father victim of Pick's disease

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Tia Willin sat staring over the steering wheel, her stomach knotted.

Her trembling hand clutched a piece of paper signed by a doctor.

Her husband — the Lee County sheriff's deputy, the Navy veteran, the Red Cross volunteer, the father their four children adored — sat next to her, his eyes vacant.

"Ryan," she said softly. "They say you're going to die."

He stared blankly.

He didn't understand. He never would.

Just shy of his 40th birthday this Wednesday, Veterans Day, he would be gone.

It had been almost 14 years since Tia met Ryan Willin, a construction worker with chestnut hair, an easy smile and eyes that changed color from green to blue.

Within three months, they decided to marry and build a life together.

Their story should have ended on a creaky porch, ice tinkling in glasses of tea, their hair graying.

"But at that moment," Tia said, "I knew life was never going to be the same."

Neither could have guessed as newlyweds Ryan would one day not remember Tia and their family. Tia never expected he would lose his job and she would lose their Cape Coral home and be forced to raise their children alone. She never imagined her faith would be tested.

But back then, neither had heard of Pick's disease.

Also known as frontotemporal dementia, Pick's is classified as rare, according to Susan Dickinson, executive director of the Association of Frontotemporal Dementias in Pennsylvania. As Tia would soon learn, caregivers often struggle with multiple misdiagnoses, ballooning health care costs and a lack of understanding.

"Someone tells you their loved one has a brain tumor, people understand," Dickinson said. "Someone tells you their loved one has frontotemporal dementia, people have no idea what that is."

There are some 250,000 cases nationally, but more people likely suffer from Pick's without knowing because of misdiagnoses.

The problem, Dickerson said, is symptoms vary depending on the part of the brain that's first affected — the frontal or temporal lobe. It's similar to Alzheimer's disease, but Pick's tends to strike younger people. Ryan was 37 when he was diagnosed in January 2007. By then, he'd already been handed

four other diagnoses.

Patients lose their memory, their ability to speak and swallow.

There is no treatment. The only prognosis is death.

“It was devastating,” said Tia, 36. “But at least I knew what was wrong.”

Ryan’s life

In the years that followed, Tia said it was hard for caregivers to remember Ryan was once a real person, not the shell of the dazed, grunting man before them.

He was the man she called Ry. The one who loved fishing, jamming to the Red Hot Chili Peppers and attending The Vineyard Church.

On weekends, he was with his children — Joel, Nathan, Jeremiah and Sarah — playing “pool shark” or huddling on the floor, giggling at cartoons.

Though Ryan grew up wanting to be a firefighter, his ambitions turned to law enforcement. He was hired in 1998 as a Lee corrections deputy.

He was known for his fairness, his character epitomized by one story a co-worker later told Tia: An inmate at the Lee County Jail stabbed Ryan in the side with a pen. As other deputies scrambled to subdue the inmate, Ryan, bleeding, turned to him and said, “I forgive you.”

Ryan was soon promoted to sergeant.

But shortly after, conditions changed.

Still searching

Ryan disappeared for hours with no explanation. He fell asleep on the job, if he showed up at all. One of his children fell and he laughed at the sight.

After a violent outburst, Tia sent him to live with his parents in Punta Gorda. In June 2006, he was fired.

Ryan refused to believe he had a problem. One of the symptoms of Pick’s is a loss of self-awareness.

It wasn’t until later that summer a minor character in a book Tia was reading leaped off the pages. The character had Pick’s.

Tia dove into research, and became convinced: the aggression, the withdrawal, the poor judgment — Ryan had Pick’s.

Another seven months passed before a brain scan proved it.

Services lacking

Many in the Lee medical community aren’t familiar with the disease, and there is no long-term psychiatric care facility for young people who suffer dementia.

“It’s a travesty,” said Dr. Fred Schaerf, a Fort Myers psychiatrist. “I think the major issue with this case

is that it really brings to the forefront the real lack of not only services in our community, but in our approach to providing good psychiatric care.

Pick's might be rare, but the symptoms are not, and all of us are susceptible to illness."

Before his diagnosis, Ryan spent several weeks at the Ruth Cooper Center in Fort Myers until he was sent to a local nursing home. He was then re-admitted to Ruth Cooper under the Baker Act, which allows people with mental illness to be held up to 72 hours. An average stay at the center is 3.2 days. Ryan's was three months.

He was taken from there to HealthPark Medical Center in south Fort Myers. He was then turned down by 35 nursing homes across the state before the Sarasota Health and Rehabilitation Center — 92 miles from his Cape Coral home — accepted him. Even then, Tia said the director once called to tell her he was sending Ryan back to her in a taxi, even though he required 24-hour care.

"They didn't understand that his problems were not behavioral, and he wasn't doing certain things just to be a pain," Tia said. "Some of the staff was fantastic, but the turnover was such that it was so difficult just to lay the foundation for a basic understanding."

An ombudsman stepped in and Ryan was allowed to stay.

Nursing home director Ed Douglass said patient confidentiality prevents him from commenting.

Schaerf said doctors are too often leaving the care of people with serious illnesses to social workers, who aren't trained to properly treat them.

"Any crisis unit should be able to treat someone with these problems," Schaerf said.

"Ryan faced an age bias because people didn't understand how someone so young could have dementia." Eventually, Ryan's pension came through, and Tia was able to secure Medicaid and Medicare.

She racked up \$30,000 in debt and lacked health insurance for the rest of the family. She sold their home and started renting. With a high school education, she began working at Publix and taking college courses.

She tried to visit Ryan at least every other week. When he could still speak, his first words to her were always about the children.

"At first it was, 'How are the kids?'" Tia said. "He would ask me that over and over. But then his vocabulary declined and it was just 'the kids.' Then when he couldn't speak anymore, we tried to see if maybe he could communicate by writing."

He scrawled one word: "Kids."

It became too hard for his children to see him.

"I want to keep my old memories of him, not fill up with all the bad ones," Joel told his mother.

In January 2008, Tia testified before a Senate committee about her experiences. Politicians promised funding for further research. They took her number. They never called.

Saying goodbye

On Sept. 8, Tia's phone rang. Ryan had a fever of 105. The disease had reached his brainstem.

"I texted my best friend in Texas with one word," Tia said. "Come."

Sarasota nursing home staffers urged her to take Ryan to the hospital. She refused. He was in a coma, dying, and there didn't seem to be any point in doing anything but making him comfortable.

As she waited for the inevitable, she was touched by a gesture of an elderly woman, Ryan's fellow dementia patient who used to shadow him as he paced the halls, when he could still walk. He was left alone for two minutes. Tia returned to find his face dripping with fruit punch, the cup cradled in his arm, sunglasses perched crookedly on his nose.

"It was actually very dangerous for her to give him something to drink," Tia said. "But all she knew was this was her friend, there was a glare in his eyes and he might be thirsty. It was one of the few moments of humanity, albeit misguided, through this whole experience."

On Sept. 10, at 10:18 p.m., Ryan died.

His death certificate indicated it was pulmonary arrest due to Pick's disease.

"With this disease, there is no validation," Tia said. "I was constantly educating the doctors and other health care workers. So to see it in print, in black-and-white, was an odd form of validation."

Tia knew Ryan would not survive Pick's. But she decided she and their four children deserved to live again. This Wednesday, Ryan's birthday, they will shop for his favorite treats: Skittles, Slim Jims and licorice. They'll package it all to send to troops in Iraq and Afghanistan in Ryan's honor.

"Sometimes I see when someone dies, they get a monument, and I wonder, 'Why couldn't Ryan have a monument?'" Tia said. "And then I remember, he has four."



Tia and Ryan Willin on their wedding day in 1993.
(Special to news-press.com)



The family of Ryan Willin has been on an emotional journey for the last 4 years since the former Lee County corrections officer was diagnosed with FTD, a fatal brain disease, and died last month on Sept 10. (left to right) Nathan,14, Sarah,10, Joel,18, Willin's wife Tia, and J.D.,12, sit in Four Freedoms Park near their home in Cape Coral. (Terry Williams/news-press.com)