

**“Seeking Ways to Find People”** [excerpted from Chapter 4, “Good for What Ails Us”]

At one of the many Super Bowl receptions in Miami in January of 2007, adoring fans gathered around former Colts’ tight end John Mackey, hoping to snag an autograph. His wife, Sylvia, a former model, five-nine and stunning by anyone’s standards, stood by his side. She somehow managed a smile each time her husband greeted an unsuspecting fan by thrusting both fists forward to show off his Super Bowl and All-Star rings. He’d point to the Super Bowl ring and, in a dull monotone, explain, “They gave me this one because I scored the 75-yard touchdown that beat the Dallas Cowboys.” She knew John wasn’t bragging; he was simply repeating one of the few things he still remembers. He would parrot the same line ten, twenty, maybe even a hundred times a day to anyone who’d listen and often to the same person.

Ten years ago, Sylvia Mackey learned that her husband’s inappropriate, repetitive, and compulsive behavior are symptoms of Pick’s Disease, a rare form of dementia. At first, John seemed a little forgetful; then it got worse. He forgot he had a sister. He sang karaoke with a stranger at a bar—something he’d never done—and afterward informed his wife, in all seriousness, that he was taking their act to Las Vegas. Once a successful sports agent in Los Angeles, handsome, congenial, and loved by all, he started to make a series of bad business calls. By the time she realized what was happening, it was too late. The man she had loved since college had unknowingly torn down everything they had built. Then in her mid-fifties, Mackey signed up for flight attendant training and proceeded to launch a new career that would pay the bills and provide health coverage....

Dementia...is a 24/7 job [for a caretaker], more demanding than infant care, especially when the “baby” is a strapping 6' 2", 235-pound man, as in the Mackeys’ case. It’s one reason Sylvia sold their home in California and returned to Baltimore, where John was something of a celebrity. “I thought it would help him hang on to his memory longer. He was still familiar with the Colts. I also know that when he got to the wandering stage, they’d know who he was.”

He has since reached that stage. At restaurants, if she doesn’t stop him, John will make off with an entire tray of pastries; in supermarkets, it’s candy bars. “If we’re at a dinner party, I know he’s going to eat his dessert and everybody else’s!” She laughs—her sense of humor has kept her sane. But some incidents she can’t dismiss quite so easily. At the airport a few years ago, when John walked through the metal detector, his rings set off

the alarm. “He had to be wanded but he refused to stand still. Instead,” she recalls in a voice still shaken by the memory, “he walked right through and kept going, like he was running through a hole in the line on the football field.” Sylvia, who by then had been flight attendant for several years, feared that in a post-9/11 world, police might be inclined to shoot and ask questions later. With officers in hot pursuit of her husband, she ran after the lot of them, screaming, “Please don’t shoot him. He doesn’t understand.” Since then, the Mackeys have traveled only by car or train.

Still, the challenges never cease. Mackey reads voraciously about her husband’s condition, so she can gauge what’s on the horizon. She knew, for instance, that the day would come when John had to use Depends. “I didn’t wait. I did it when he was still in a state where he would accept it.” To get him to comply, she told him that the NFL had sent “special underwear.” She also refers to his daily medication as “NFL vitamins,” because “anything that’s NFL-mandated gets obeyed!” But for all her personal strength and resourcefulness, she knows she can’t do it alone. “You start seeking ways to find *people*.” Research confirms this wisdom: Caregivers who have lots of social ties are at less risk for mental health problems.

Mackey’s youngest daughter has been a great help, but others in their inner circle now feel uncomfortable around John or don’t know how to react to his mental decline. Some of the couple’s old friends limit their visits, and social invitations are rare. Thus, Mackey has come to rely on consequential strangers: the daily home aide, the retired police officer who stops by to “sit with John,” the staff at the senior care center, members of the various Alzheimer’s support groups she has attended, and wives of other NFL players who share stories about their own husbands’ mental decline. A select group of work colleagues also know about her situation. But of all the wonderful people who’ve kept her going, it’s the gang at the Mount Washington Tavern in downtown Baltimore who allow Sylvia Mackey to regain a momentary sense of normalcy. They remember John as the football hero he once was but also accept him as the genial, simple man he has become. “The place is just like *Cheers*,” she quips. The owner started carrying non-alcoholic wine for her. There she can let John belly up to the bar with a twenty-dollar bill in hand. “He can order his own glass of wine, like a man, so he can preserve his dignity. And if he wanders off, someone always keeps an eye on him,” she adds. “It’s such a relief not to have to be in charge every minute.”