

To the Front Step and Beyond

Finding Ways to Keep on Keeping On

In November of 2012, Bill Hinkle walked out the front door and picked up the newspaper. An everyday occurrence for most people, this simple act filled him with a great sense of accomplishment. Just a week earlier, Bill's Parkinson's had made it difficult to walk around the house with two walking sticks. He and his wife Corrine had been considering a wheelchair.

Bill refers to his improvement as "getting normal" rather than "getting better." He had received treatment in Denver, Colorado, that allowed him to do simple things he never thought he'd be able to do again. What Corrine noticed the most were the returning facial expressions—quirks that she'd almost forgotten existed.

But the Hinkles emphasize that their real story is the story of the people they've met and the experiences they've had along the way.

A strong family

When Bill was diagnosed with PD in January 2005, he and Corrine had been married 44 years. They'd met at the milk machine in the cafeteria of William Penn University in Oskaloosa. Bill had come from his home state of Pennsylvania to Iowa, the state with "nothing but blizzards," according to his aunt. Corrine had grown up in nearby New Sharon. They were married while still in school; Corrine graduated a year ahead of him, and got a teaching job in Grinnell. For a year, they lived together in Grinnell, and Bill commuted back to Oskaloosa for classes, student teaching, and football practices.

After Bill's graduation, they both taught in Grinnell for two more years before moving to Dike, where they have lived ever since. Bill taught sixth grade and coached everything "except wrestling" at the school, including starting a girls' cross country and track team. Corrine taught fourth and fifth graders for a total of 35 years. According to Bill, she was the kind of teacher everyone hoped they'd get. "People jockeyed for a position in her class," he said.

The Hinkles had three children, two boys and a girl. They loved to travel, and made great memories travelling around the country together. During these years, Bill developed a love for road biking, a love which he passed on to his daughter Nadine. As a young girl, she watched him participate in RAGBRAI, having fun and making good friends. She took her first "long" bike ride when she was about ten. With a school friend, decked out in what she thought was the coolest biking gear, Nadine rode 40 to 50 miles from Dike to Eldora—with dad following along in the family's Suburban, ready to offer support if needed.

In high school and college, Nadine rode in RAGBRAI alongside her dad several times. Years later, when Bill was diagnosed with Parkinson's, Nadine would use this shared love for biking to help support him.

Learning to live with Parkinson's

There came a time when Bill noticed he was having more trouble finishing RAGBRAI. There were other troubling signs as well. As church treasurer, he found it was becoming more difficult to sign checks. It was also taking him longer to sort mail at the post office, where he was then working. In January 2005, Bill was diagnosed with PD, and he retired in September.

Bill and Corrine were not completely new to Parkinson's. A good friend, Maureen, had been diagnosed with PD earlier, and they had watched her struggle with it. Corrine, in fact, had been a caregiver for Maureen—they'd hang out together, and Corrine would help her shop. Both Bill and Corrine remember the pain Maureen felt for them the day they told her Bill's diagnosis. She knew what they'd be facing on the road ahead.

Maureen did give them the inspiration to meet the disease head-on. When Maureen was diagnosed, there was no support group, and very little knowledge about PD available for her. The Hinkles decided to be their own advocates, and advocate for others at the same time. As they visited the offices of doctors in Iowa who treated PD, they noticed there was no information about PD in the waiting rooms. Though they met many doctors and nurses who were caring and conscientious, the Hinkles often felt they were educating the professionals.

To learn about the most up-to-date research and treatment practices and to meet others in their situation, they attended the annual Parkinson's conference in Des Moines. There they met Sam Irwin, then coordinator of the Iowa Parkinson's Disease Association. They were put in contact with PD specialists in the state, such as Doctor Lynn Struck.

As they learned more, they looked for a way to share their knowledge with others. They first started a support group for PD in Dike. With donated funds, they also supplied every library in Grundy County with books and pamphlets on PD. Donations have also helped defray the cost of attending conferences for some members of their support group.

They also emphasize the importance of research, and fundraising to finance it. “Hope is fine, but it’s the dirty dollar bill that gets things going,” says Bill. Nadine has embraced this philosophy wholeheartedly, participating in biking fundraisers. For several years after his diagnosis, Bill participated in Pedaling for Parkinson’s in RAGBRAI. When he was no longer able to do so, Nadine picked up the mantle and rode in honor of her dad. She was overwhelmed with the support shown for both her and her dad—in one year, she raised over \$5,000 for Pedaling for Parkinson’s, which supports Parkinson’s research and education.

In June of 2012, Nadine participated in Ride the Rockies as part of the Davis Phinney Foundation for Parkinson's Team. She raised around \$4,100, and enjoyed telling her dad about the experience. “Ride the Rockies was on my dad’s Bucket List, and now I can help give him a taste of it,” says Nadine. She plans to participate in Ride the Rockies in 2013 as well.

A new beginning

In November of 2011, Bill underwent deep brain stimulation (DBS) surgery at the Mayo Clinic. He worked with a programmer at the clinic to fine-tune the electrical impulses running to his brain. However, he and Corrine weren’t totally satisfied with the results. Instead of experiencing a delayed progression of the disease, Bill was falling while walking even more often. His family was worried that it was only a matter of time before he was seriously injured in a fall.

Despite his condition, Bill and Corrine travelled to Colorado for the Victory Summit conference put on by the Davis Phinney Foundation in November 2012. Nadine had moved to Colorado after graduating from college, and attended the conference with them. There they met doctors, specialists, others with PD, and Davis Phinney himself. Phinney, an Olympic-winning cyclist, had been diagnosed with early-onset Parkinson’s in 2000, and started his foundation to raise money to support programs and research, as well as spread information and tools to help people with Parkinson’s and their caregivers manage the disease. The Hinkles also met Doctor Sierra Farris.

Doctor Farris, who works at the Movement and Neuroperformance Center in Denver, listened to Bill’s troubles with the DBS surgery and recommended that he see her. Though Bill and Corrine weren’t sure it would be worth it, Nadine convinced them to go. “She told us, ‘That car is not leaving this state until you go talk to her,’” remembered Bill. It turned out to be one of the best decisions they ever made. Within hours of the first session, in which Doctor Farris reprogrammed Bill’s DBS battery, he noticed he had a better stride, balance, and energy, and that his facial expressions, many of which the family hadn’t seen in years, were coming back.

Corrine noted that while they both acknowledge that death is inevitable for everyone, she distinctly remembers what Bill said as they walked out of Doctor Farris’s office the first time: “I think she saved my life.” They had both concluded that it was only a matter of time before one of Bill’s falls resulted in injury or death.

What Bill appreciated most about his new quality of life was the ability to do normal things, like getting the newspaper without two walking sticks. Before had they left for Colorado, Bill lost one of the walking sticks. “God must have known we weren’t going to need it anymore,” he laughed.

Keep on keeping on

In the years since his diagnosis, Bill has had time to reflect on the good that has come his way. He doesn’t feel that God has given him this disease as a punishment, but rather to see what he would make out of the situation and his life. Reflecting on his original response to his diagnosis, he said, “I held two pity parties, and nobody showed up.” After that, he realized how lucky he was—starting with his amazing support team, headed by his wife. As his caregiver, Corrine has been with him every step of the way, educating herself, pushing him at times to do things he didn’t want to do, even doing exercises with him that help manage his disease.

However, he noted, “We were partners, working through life together even before I was diagnosed.” Though they can get grouchy with each other at times, especially when Corrine is trying to make him do something he doesn’t want to do, she has come up with a clever solution—she has trained the grandkids to remind their grandpa to do things like take “big steps” and count his steps.

Likewise, if he hadn’t been diagnosed, both Corrine and Bill realize they would never have met many of the amazing people they now know. They call these people their angels—the doctors, nurses, specialists, family members, other Parkinson’s patients and their families, and many more. And they realize while they have been fortunate in their journey, many others don’t have the same support or access to knowledge. So they have kept their support group going, and they continue to promote their favorite slogan: “Keep on keeping on.”

As for the future, the Hinkles will return to Denver this April for another session with Doctor Farris. This year Bill plans to participate, albeit briefly, in RAGBRAI on his three-wheel bike. With his support team at his side, he will keep active as long as possible, dancing, biking, and walking to the front step and beyond.