

When the Sky is Gray

The story of Barbara Clausen

At Whirlpool Corporation's international headquarters in Benton Harbor, Mich., staff personnel have a fine vantage point. Perhaps more than her colleagues, Barbara Clausen appreciates the view. Not a working day goes by that she fails to glance out at the vast expanse of blue-green water that forms Lake Michigan.

Barbara checks out of her office at half past four each afternoon and heads for home in nearby St. Joseph. As she drives south on highway M-63, she passes her favorite stretch of lakeshore—Tiscornia Beach. Hundreds of times in the last twenty-five years, Barbara has stopped here for a few moments of solitude. She observes the sailboats, which retreat to the harbor when the water gets rough. She weaves her way through the

fishermen, who cast their lines from the lighthouse pier. Sometimes she just rests on the sand and watches the waves.

Postcards portray it bathed in sunshine, but Lake Michigan can easily become a theater for bad weather. Barbara enjoys the show. She visits the deserted beach when there's a good summer rainstorm. She comes back in the fall, when the sky is gray, the wind packs a chill and blowing sand stings her face. And she braves the bitter cold of January and February to admire winter's silvery landscape.

This was also Paul Clausen's hideaway. Even after Huntington's disease began to ravage his body, he cherished his excursions to the lakefront. Only when Barbara



Barbara Clausen has a deep appreciation for nature—and especially for Lake Michigan, which has been a source of inspiration to her.

could no longer transport her ailing husband across the sand and down to the water did his visits to Lake Michigan end.

But Barbara's continue. She hikes along the shore, dodging waves as they crash in on the beach. She walks out to the lighthouse and hears the foghorn sound its warning. Now and then she scales a sand dune and studies the horizon. And she is thankful for this sanctuary, this place of refuge, where she finds strength and courage to carry on.

For Barbara has needed such qualities. While she professes not to be a particularly strong or courageous woman, her friends and acquaintances know otherwise. They know how she shared her husband's agonizing, 25-year battle with Huntington's disease. They know that her son David now lies in a nursing home, stricken by the same incurable illness. They know she has worked a full-time job while raising a family, and that she has collected thousands of dollars for Huntington's disease research.

And though they can't completely understand it, they know she has not allowed bitterness to defeat her spirit.

Even as a youngster growing up in Keokuk, Iowa, near the Mississippi River, Barbara Taylor learned some early lessons about hardship. When her father developed Parkinson's disease in the late 1930s, the family migrated to Dayton, Ohio, in search of medical assistance. It could not be found, and the elder Taylor spent the rest of his days bedridden.

But help of another kind materialized in 1938 when Barbara's mother tuned in a local radio broadcast. The speaker, who identified himself as Dale Oldham, pastor of the First Church of God, reminded Mrs. Taylor of the circuit-riding Methodist preachers in her own background. She mailed him a dollar or two, enclosing a note of concern about her unchurched family and her husband's poor health. Several days later Rev. Oldham came calling.

The Taylors embraced the church. And in 1945 Barbara heard about Anderson College when the Rev. E.E. Kardatzke visited Dayton and attended a high school basketball game with the young people. "All of you ought to go to Anderson College when you get out of school," he told them.

Barbara did exactly that, moving to Anderson the summer she graduated from high school. Her widowed mother, as well as her brother Bud and her sister Madelyn, went along. Money being scarce, Barbara studied part-time and worked for a church agency.

She met Paul Clausen during campmeeting. "I was working in the World Service tent when this young fellow came sprinting up to the counter and asked to use the telephone," Barbara recalls. "I told him no, it was for office use. He said, 'Do you know who I am? My dad is a professor at Anderson College.' I said, 'What does that mean to me?'"

The debate continued for some time before Barbara asked what was so urgent. Smiling, she recounts the

exchange: "He looked at me with a sparkle in his eye and said he had just wrecked his dad's car. I asked him how on earth he did that and he grinned. He said he was watching a pretty girl walk down the street." Paul placed his call.

The next time they saw each other, they were in line to register for music classes. "He walked up and said I was the one who wouldn't let him use the telephone," Barbara relates. "We started talking, and one thing led to another. The next thing I knew I had a date to go skating with him. That's the way it started."

It continued in grand style at Park Place Church of God on April 6, 1950, as the Rev. Dale Oldham pronounced them husband and wife.

The newlyweds remained in Anderson for a couple of years to continue their schooling. Paul graduated from college and attended seminary, while Barbara took classes she thought would be helpful to a pastor's wife.

In 1952 they moved south to New Albany, Ind., where Paul took his first job as minister of music and youth. A baby daughter, Karen, arrived in July of 1954. Paul accepted a pastoral position the following year in Canton, Ohio, but his ministry there was interrupted by a promising opportunity.

Endowed with a wonderful baritone voice, Paul had been singing with the Christian Brotherhood Hour Quartet. In 1957 the group met up with Fred Waring and the Young Pennsylvanians, one of the most popular musical acts in the country. Waring asked the Quartet to go on the road with him and perform gospel music as the Glory Voices. They did, later singing at the White House for President Eisenhower, Queen Elizabeth II and Prince Philip. But the Quartet returned home when asked to appear in a Christmas show that was to be sponsored by a cigarette company.

Paul, Barbara and Karen—and by now a newborn son, David—spent the next several years in California before accepting a pastorate in Lincoln Park, Mich. It was winter, 1961. And it was time for Huntington's disease to unleash its destruction.

At first, Barbara dismissed Paul's personality changes as inconsequential. Perhaps, she thought, he was merely having a bad day. But the bizarre symptoms multiplied and Paul became plagued by anxiety, depression and loss of interest in his job and family. His body faltered, as well.

"He would go out and make calls in the afternoon," Barbara says. "I can still remember him coming home later in the day with his face looking so white and drawn. I'd open the door and he would literally stagger across the room and fall on the couch."

Doctors concluded that Paul was under too much stress or was in the wrong line of work. Or perhaps he lacked an essential vitamin. They could do nothing to help, however, and Paul's deteriorating condition forced him to resign from the Lincoln Park church. The family moved to St. Joseph in 1964, hoping that a

change of scenery would do some good. But matters only got worse.

Although Paul knew that his mother suffered from Huntington's disease, he had trouble facing the prospect that he could have inherited the defective gene.

"Paul would insist that he couldn't get the disease," Barbara explains. "He was thinking that since his two sisters and his mother already had it, surely it couldn't happen to him. He would get angry if I suggested that it could."

In 1965, unable to put it off any longer, Paul agreed to undergo testing at Mayo Clinic. He was thirty-five years of age when he heard the news. The degenerative brain disorder was already attacking his central nervous system, ruthlessly laying waste to his body and mind.

For some time Barbara feared that Huntington's would also crush his spirit. As his world collapsed around him, Paul prayed desperately for a physical healing which never occurred. Anger and resentment overwhelmed him, triggering a mental breakdown in 1968. He was admitted to a psychiatric hospital for treatment.

The lowest point came in 1970 when, after a weekend outing, Barbara was returning her husband to the hospital. "He tried to jump out of the car on the highway," she relates softly, "and he tried to steer us into the ditch. He was saying that he wasn't going to live like this, and that he didn't want me to, either."



ROGER SCHER WHIRLPOOL

Paul Clausen (inset) as he appeared in 1962. A more recent photograph shows Barbara with her son David and daughter Karen Denmark. Karen, who attended Anderson in 1972-74, is married and lives in Mattawan, Mich.

That afternoon the hospital staff advised her to walk out and never come back. It only made it harder for Paul, they insisted, when he saw her and the children.

Barbara spent a restless night wondering if she would ever see her husband again. "I remember praying that somehow he could accept what was happening to him so that I could still take care of him," she says. "He had nobody else." Near morning, her troubled mind cleared and she drifted off to sleep.

The next weekend as she approached the state hospital grounds, she saw a figure at the end of the driveway. Drawing closer, she realized it was Paul. "I pulled the car up and stopped, and he came toward me," she recalls. "His face had a totally different look. He was relaxed, smiling. I jumped out of the car and I embraced him and asked what had happened."

Paul's ability to speak was impaired, but he managed to communicate. The previous week, he indicated, he had been sitting alone on a hospital bench, certain that Barbara would never return. He was leaning forward with his head in his hands when he felt someone sit down next to him. He looked up. The bench was empty.

"He quivered and shook as he told me about it," Barbara states. "He said it was the presence of God. He said God was back with him again and that he wasn't afraid to die anymore. We got in the car and went for a ride. We sang all the duets we had ever sung. We sang parts, held hands, just had a wonderful time. I must have had him out four or five hours. When I took him back I told him I'd return Wednesday. He said he knew I would. He quietly turned, put his hands in his pockets and

walked back in. Never, not for a moment, did he go back into that old frame of mind again."

His spiritual and emotional healing notwithstanding, Paul's physical condition worsened in the ensuing years. Barbara stood by helplessly as her husband, once a sturdy, robust man of more than 200 pounds, wasted away to skin and bone.

In the early days of Paul's illness, Barbara resolved to combat the dread disease. "I can't remember a specific day, but someplace along the road I made up my mind that if I had to give the rest of my life to find some answers, I was going to do it," she says.

Shortly after folk singer Woody Guthrie died of the disease in 1967, his widow, Marjorie Guthrie, founded what later became the Huntington's Disease Society of America. Barbara made contact with Marjorie and immediately went to work. She helped establish a Michigan chapter of the organization and has served on the national board of trustees for nearly twenty years. She is also one of the organization's key fundraisers. In 1986 she received the President's Award from the Society for single-handedly raising more money than any other individual. To date, she's been responsible for bringing some \$30,000 into the organization's research budget.

Contributing a sizable portion of that total has been Whirlpool Corporation, where Barbara works as a qualitative survey research analyst. The company recently honored Barbara as one of its "Most Valuable Volunteers" for her efforts in fundraising, public speaking and counseling Huntington's families.

"What I've done has made a difference, I know that," Barbara says. "And someday there'll be some answers. There just have to be some answers."

Paul Clausen's heart-rending struggle with Huntington's disease ended on March 14, 1987. Yet there is no respite for Barbara, who watches the disease claim another victim—her son. David, now 30 years of age, was in high school when Huntington's struck. He tried to study music at Anderson for a time but failing health forced him to quit. Then through a newsletter, he met a Florida girl who also had the disease. They married and spent two years together before they could no longer manage on their own. "It's a memory he has," says his mother. "It made him feel that life hadn't entirely passed him by." David recently moved to a nursing home where he can receive 24-hour attention.

Barbara also lives with the constant fear that Huntington's disease will strike Karen, her daughter.

In the face of such tragic circumstances, Barbara could easily have turned bitter. But instead, she has gracefully endured her sorrow.

"I guess my philosophy is that as long as we're in this world, many unfortunate things are going to happen to us," she says. "Cancer, diabetes, Parkinson's, Huntington's—if you're living on this earth, something is going to hit you at one time or another.

"I don't blame God for it as some people do, I never would have made it if I'd have had that kind of a

concept of God. To my way of thinking he's a God of love and compassion. He's there to help you through."

Barbara's religious faith and "a tremendous support system of church, family and friends" have enabled her to keep smiling, in spite of her situation.

"I went through some bitter experiences in the beginning," she admits, "but finally I just said to myself: You're going to have to live like this. You can either lie here and be a depressing old woman that nobody wants to be around, or you can get out and do something with your life, have friends and make the best of it."

Though many of her fifty-nine years have been filled with suffering, Barbara Clausen *has* made the best of it. She's done so with courageous determination, an unwavering faith and an indomitable spirit. And, every so often, a pause for renewal at her lakeshore refuge.

Huntington's: an incurable disease

The disease that Barbara Clausen works to eradicate takes its name from Dr. George Huntington, who in 1872 provided an early but substantially complete description of the illness.

Known to have been in existence at least since the Middle Ages, the disease was originally known as chorea—from the Greek word for dance. Most people who suffer from Huntington's writhe, twist and turn in constant and uncontrollable dance-like motion. It affects the mind as well, impairing or destroying one's ability to talk, think and reason. Brain cells are destroyed as HD attacks the central nervous system.

The incurable disease, which knows no ethnic or geographic boundaries, is genetically transmitted from parent to child. Each child of an afflicted parent has a 50 percent chance of inheriting HD. If the child does not inherit the defective gene, the chain is broken.

Although Huntington's can set in at any time, symptoms generally begin to appear between the ages of 35 and 45, and grow progressively worse for 10 to 20 years. The victim, susceptible to other illnesses, commonly dies of pneumonia, heart failure or other natural causes.

The Huntington's Disease Society of America estimates that 50,000 people in the United States are afflicted and 100,000 are at risk.