

AGING TODAY

Vol. XXV, No. 6

PAGES 11 & 12

November–December 2004

ISSN: 1043-1284

www.agingtoday.org

'ALZHEIMER'S IMPOSTOR' HITS 375,000 WITH REVERSIBLE ILLNESS

By **PAUL KLEYMAN**

Robert G. "Bob" Fowler, at age 73, is a hale and strapping lifelong oilman, the 1988 inductee into Texas industry's Roughneck Hall of Fame. Today the former president and chairman of Enserch Exploration Inc., parent company of Lone Star Oil and Gas, runs RGG investments with his son, Bob Jr. He hunts and golfs enthusiastically, travels extensively, devotes as much time as possible to his granddaughter-and is generally ambulatory after nearly a decade of deterioration that left him misdiagnosed with Parkinson's and Alzheimer's. Fowler is also an avid and articulate evangelist spreading the news about Normal Pressure Hydrocephalus (NPH), sometimes called the Alzheimer's impostor.

"In the early '90s, I started having a variety of problems that were irritating, confusing and troublesome," Fowler told a press gathering earlier this year. He would inexplicably stumble and fall, his hand-eye coordination waned and he lost physical dexterity. Urination became so frequent and urgent that it seemed as if Dallas golf courses lacked "enough trees to handle some of those emergencies." His attention span shortened, and waves of drowsiness endangered his safety when the sound of a car began lulling him to sleep. On a drive to Houston, Fowler dozed off with the cruise control set to 70 miles per hour. He woke up careening down the middle of a roadside ditch. Miraculously, he was able to brake the car without damage or harm to himself and his wife, Bonita.



Bob and Bonita Fowler.

WAKE-UP CALL

Fowler was among speakers at a presentation held by the National Council on the Aging (NCOA) earlier this year. "What if one in 20 or as many as one in 10 people diagnosed with dementia in fact have a reversible, treatable condition?" asked NCOA president and CEO James P. Firman. The news that NPH, once called water on the brain, often can be cured if correctly diagnosed "should be a wake-up call to the medical community, caregivers and long-term care providers to be on the lookout for it." Most people who develop NPH are over age 60, with the median age of onset being the early 70s.

When Firman first learned about NPH last year, he was alarmed to discover that almost none of the experts in assisted living or adult daycare he talked to had heard of the ailment. Firman said his mother's diagnosis last year with what turned out to be vascular dementia made him especially sensitive to the need for public awareness about any glimmer of hope patients and their families might have that at least some dementia is reversible. He added, "We need to make sure that the symptoms of NPH are recognized as early as possible to avoid sending patients down the wrong path."

Dory Kranz, director of NPH and Older Adult Services at the Hydrocephalus Association in San

Francisco, observed, “The lucky ones like Bob Fowler are able to be their own health advocates or have a loved one advocating for them. They keep asking the same questions of different doctors until they find out what’s wrong.” Although only 11,500 people last year had the surgery that can repair NPH, she said an estimated 375,000 people, or about 5% of those diagnosed with dementia, actually have the ventricles in their brains ballooned with excessive cerebrospinal fluid (CSF). This fluid frequently can be drained with a surgically implanted shunt to restore a patient’s ability to function. “With proper treatment, the vast majority can transform from being an embarrassment to themselves and a burden to their families—perhaps in or on their way to a nursing home—back to being contributing members of society,” she said.

THE HARD WAY

Kranz added that she learned of NPH the hard way, through the experience of her father-in-law, Dick Kranz. It took at least six years from the onset of his gait problems and related difficulties to get a correct evaluation. A brain scan is critical in determining whether a patient at risk for NPH actually has this condition. In fact, Dick had a brain scan in 1992, but the radiologist was looking for a carotid artery problem and “failed to recognize the enlarged ventricles,” she said. Although ventricles can increase in size with normal aging, the butterfly-shaped image that appears in brain scans of people with NPH should always be a signal to test for that illness.

In the ensuing years, one doctor attributed Dick’s walking problems to rheumatoid arthritis, Kranz said. Another brushed off his medical decline as malaise, and still another diagnosed senility. Some physicians said things such as, “You’re 70 years old, what do you expect?”

In addition, Kranz recalled, “Dick and my mother-in-law conspired to keep the embarrassing incontinence from us and the doctors,” concealing a major symptom. The bladder problems, added to the brain and balance difficulties, might have been an earlier tip-off that a neurological examination was in order. It was not until 1998 that a neurologist “noticed the way Dick shuffled his feet, as if they were stuck to the floor,” Kranz said. The specialist asked about mental confusion or memory problems and broached the embarrassing subject of urinary urgency and incontinence. A brain scan led to the diagnosis of NPH. The surgery was almost immediately successful; however, Dick soon became a victim of a rare but serious complication—a fatal stroke. Kranz said that careful monitoring for this postsurgical problem can minimize or prevent serious or terminal consequences.

“If any one of the symptoms is evident, NPH should be considered and ruled out before moving on to a diagnosis of dementia or Alzheimer’s disease,” said Anthony Marmarou, professor and vice chairman of the Medical College of Virginia in Richmond and a leading NPH researcher. “Too many people may be living with NPH and suffering needlessly,” he added. Key tests for NPH include a complete neurological workup, which may include clinical assessment and a brain scan, either with a computerized tomography (CT) scan or magnetic resonance imaging (MRI), and a brief test for CSF flow, among others.

Marmarou said his research shows that about one in seven patients in nursing homes or extended care facilities may be at risk for NPH. “This is an amazing number,” he stated. A study he and his colleagues conducted of 151 patients with NPH found that two-thirds (100) improved with temporary drainage. That group then underwent surgery to implant a programmable shunt, which diverts excess fluid usually to the abdomen, where it is absorbed into the blood or otherwise eliminated. The programmable shunt enables a neurosurgeon to adjust the pressure level noninvasively every few months with a quick procedure using a magnetic device. In the Virginia study, 91% of those who underwent the relatively simple surgery benefited from the implant.

DESPAIR IS LIFTED

The programmable shunt was still a fairly new innovation in 1999, when Fowler was finally diagnosed with NPH. Initially, he had two unsuccessful surgeries using the earlier fixed-pressure shunts. He recounted his deepening despair until a crashing, backward fall onto a table in his doctor’s office pointed to a neurological condition.

Until that sudden tumble—“I broke everything on that table, but somehow both the table and I survived”—Fowler’s situation had become “beyond disappointing,” he said.

In early August 1999, Fowler fell while shuffling to the bathroom at about midnight, and lay on the floor until Bonita found him in the morning. Unable to lift her Texas-size husband, the petite woman phoned their son for help. “It was unbelievably humiliating to go through things like that,” Fowler said. He agreed with Bonita and Bob Jr. that placement in a nursing home would be the best option for him.

Most anguishing for Fowler was his inability to safely dote over his then-two-year-old granddaughter,

Emma Elizabeth. At one point he fell, nearly hitting her. “As I concluded that I was not going to get better, I wrote her a love letter from Grandpa to be saved and read to her or given to her when she could more clearly understand. I expected to be gone by then, and I wanted her to know how much I loved her and that I wanted to do so many things with her but couldn’t. I wanted her to remember me in as positive a light as possible.”

His health completely broken, Fowler wrote his own obituary. “I selected pall bearers; I was totally convinced that the end was near for me.” But a doctor’s visit and the fateful fall at the neurologist’s office led to his having an MRI and finally being diagnosed with NPH.

“The programmable shunt has allowed Bonita and me—after almost 10 years—to resume an almost completely normal life. I can hunt, I can play golf, I have an incredible relationship with my beautiful now-six-year-old granddaughter. We’re active in our church. We can go to the movies. We can eat out. I’ve been able since that surgery to resume an active role in our company. I serve on several corporate boards, as well as on the advisory board of the engineering school of the University of Oklahoma. And I even serve on the enrichment foundation for high schools in the Waco and Central Texas area. Those are things I couldn’t have dreamed of doing a few years ago,” Fowler said.

For more information about NPH, visit the websites at www.allaboutnph.com and www.hydroas-soc.org.