People, not patients

New research suggests that people with dementia are much more aware of their condition than was previously thought. Now we need new models of care. BY JESSICA WAPNER

PHOTOGRAPH: TODD WARNOCK/CORBIS

OTTO BIGNELL HAS HELPED TRANSFORM THE HOFWIJCK NURSING HOME IN THE DUTCH CITY OF LEIDEN. THROUGH HIS FOUNDATION, VOLUNTEERS ORGANIZE TRIPS TO THE BEACH FOR PEOPLE WITH DEMENTIA.

PHOTOGRAPH: SASJA CORNELISSEN

"People with dementia know and feel and experience much more than we generally tend to think. And if that's true, then we need to listen to them about what they want and what they need."

OTTO BIGNELL, ELDERLY CARE PIONEER

"I KNOW THIS HAS BEEN HARD ON YOU." It had been two years since Butch (not his real name) had said anything, which only made these words, among the last he uttered to his wife and daughter before he died, all the more poignant. Over the years, they had always thought they saw recognition in his eyes, had always believed he knew who they were and who he was. But that one sentence confirmed it. This man, a late-stage dementia sufferer in his 80s who took part in a family support program at Duke University Medical Center, was aware of what was happening to him.

An increasing body of evidence supports the notion that people with dementia are aware, to varying degrees, of their condition. These new insights are a departure from the traditional view of dementia as an all-consuming state that erodes our knowledge of self and others, and they have radical implications for the care of people with all forms of dementia. The shift is leading to a reduction in the use of prescription medications, improved interpretation of behavior and a range of pioneering activities in the nursing home environment.

At the root of this movement is a growing determination to treat people with dementia as human beings, not as patients. "People with dementia know and feel and experience much more than we generally tend to think," says Otto Bignell, co-founder of the Dutch non-profit Springlevend (Prime of Life), dedicated to improving elderly care. "And if that's true, then we need to listen to them about what they want and what they need."

Dementia literally translates as "deprived of mind." Once considered part of the normal aging process, the condition is now widely recognized as an abnormal state linked to Alzheimer's disease, stroke, Creutzfeld-Jacob disease and other neurological ailments. In Alzheimer's, malfunctioning proteins lead to the formation of tangles, also known as plaques, which impair how the brain's neurons work. As these tangles profligate, the mass of the brain diminishes. Upon death, an Alzheimer's-affected brain weighs, on average, 40 less than a healthy brain.

This neurologic degradation results in the loss of so-called executive function, which is governed by the brain's frontal lobe. As a result, routine activities like brushing your teeth or cooking a meal can no longer be accomplished, familiar facts can no longer be recalled and well-worn routes can no longer be followed. People with this increasingly severe cognitive impairment can have trouble remembering faces and names—including those of loved ones—and often lose their ability to communicate fluidly with language.

The emotional and economic cost is immense. Family members struggle to care for people who require vast amounts of time and consideration but who may fail to recognize them. As the impairments advance, people with dementia may suffer from delusions and erratic, sometimes violent behavior. According to the *World Alzheimer Report 2012: The Global Economic Impact of Dementia*, issued by Alzheimer's Disease International, dementia affects an estimated 36 million people worldwide. The estimated cost for the medical, social and informal care of dementia in 2010 alone was $604 billion. With the oldest baby boomers now reaching 65, the cost is only expected to escalate.

In the 1970s and 1980s, as Alzheimer's-related dementia among the elderly increasingly caught the attention of the medical establishment, the dominant approach to care was to keep people "clean, dry and fed, and manage their behavior through chemicals," says Anna Ortigara, director of communication and outreach for the Green House Project, which builds and runs small group nursing homes. "We overused medications; we overused restraints," says Susan Frick, who runs Without Warning, a counseling group for early-onset Alzheimer's patients and their families. "I remember people being highly agitated, and I know it was because of our approach to them."

Gradually, research highlighted a new paradigm of care based on the idea that the behavior of those with dementia has meaning. "If they become upset or frustrated or push you away or scream, that's not meaningless," says Ortigara. "They are telling us that they are not in well-being."

First-hand accounts of dementia also helped change perceptions. Richard Taylor, a psychologist diagnosed with Alzheimer's-type dementia at age 58, wrote *Alzheimer's from the Inside Out* to demystify the experience of living with the disease. Christine Bryden, an Australian who was a science advisor to her country's prime minister when she was diagnosed at age 46, wrote two breakthrough memoirs, *Who Will I Be When I Die?* and *Dancing With Dementia*. Other chronicles, such as *Losing My Mind* by Thomas DeBaggio have become part of a growing body of literature showing that people with dementia are aware of what is happening to them.

Otto Bignell became convinced that dementia sufferers were far more conscious and capable than the traditional care model assumed back in the 1990s. In 1997, he'd taken a job as an accountant at Hofwijck, a nursing home in Leiden, Holland, simply because it happened to be the first one listed in the newspaper. At first, he stuck to number crunching. But he found it impossible to ignore the plight of the residents. Some were far from home. Some had few visitors and nowhere to go. Many were sad and unwell. He began walking the hallways just to be available for conversation. "I realized that, being a human, I'm responsible for the situation I'm in," says Bignell, a slight 45-year-old with kind brown eyes.

It was during those hallway conversations with residents that he became increasingly aware of their awareness. He noticed how some could suddenly speak lucidly about their lives. He saw how walks in the woods and other activities revived their spirits and senses. He also saw how the nursing home environment left few opportunities for physical exercise and little time for the one-on-one care that had led him to this understanding.

Bignell began researching dementia and consulting with colleagues to see what improvements could be made at Hofwijck. But there was only so much he could do as an accountant. So in 1999, as Bignell was immersing himself in research, the facility expanded his position, making him responsible for activities, volunteers and the residents' well being. In Bignell's new role, he was free to try new ideas to enrich the lives of people who, though impaired, were still cognizant. Based on the simple premise that anything calming would help, he began simply—by installing a fish tank.

The two-meter-wide aquarium quickly became a focal point for residents. It helped reduce aimless wandering, a perennial problem among the memory-impaired. Although Bignell, neither a scientist nor an elder care professional, was just proceeding by instinct and common sense, his ideas now have substantial scientific support. A 2010 study published in the *Journal of Nervous and Mental Diseases* demonstrated that live and animated stimuli prompt longer and livelier engagement among people with dementia compared to non-living, immobile stimuli such as wall paintings. The authors also documented a substantial reduction in agitation associated with the presence of live stimuli. "If you get the environment right, it can decrease many of the signs of dementia," says John Zeisel, a sociologist and author of *I'm Still Here: A New Philosophy of Alzheimer's Care*.

The typical nursing home environment tends to exacerbate cognitive problems, says Allen Tacke, a geriatric mental health specialist with Seattle-based NAVOS, a non-profit that counsels nursing home residents with and without dementia. "Residents live in an atmosphere with two or three televisions in one room, alarms beeping, people shouting in the hallway," says Tacke. "The brain gets into a toxic fog because they are not in an environment where negative stimulations are lowered and good stimulation is put in." Over the years, Tacke has noticed a trend toward creating a more pleasing environment using indoor fish tanks as well as natural lighting and fountains.

Bignell notes that brightening the lights can also reduce the stress of not being able to see well, an adjustment that, though not instituted at Hofwijck, has been made at other pioneering facilities, such as Beatitudes in Tucson, Arizona. A randomized trial by the Netherlands Institute for Neuroscience found that brightening the lights at dementia facilities reduced cognitive and non-cognitive symptoms of dementia. Among 189 residents at 12 group homes, those at the facilities where light exposure was increased experienced less cognitive decline, fewer mood swings and reduced agitation compared with residents at the homes where the lights were not adjusted.

With the help of volunteers, Bignell also started a weekly foot-washing program to restore the physical intimacy that many elderly people no longer experience. Residents flocked to their weekly soaks. "Regular physical care is often constricted by time and economy, so the extra time and attention was a major success," says Conny Plomp, former manager of care at Hofwijck.

Science is confirming the value of intimate contact for dementia patients. A 2007 study published in the *Archives of General Psychiatry* found a link between loneliness and increased risk of Alzheimer's disease. Among 823 seniors tracked for four years, those who reported the highest degree of loneliness had a twofold or higher risk of developing the condition compared to those who reported only slight feelings of loneliness.

To provide education and entertainment,

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ALLEN TACKE, GERIATRIC MENTAL HEALTH SPECIALIST, NAVOS

Bignell and an increasingly dedicated team of volunteers created an audio library with recordings made by volunteers on everything from gardening and history to coping with fear and grief—activities that focused on the person rather than the patient. "Giving people access to creative learning situations, whether it be art, music, stories, new and familiar topics, is using the part of the brain that works, as opposed to focusing on what doesn't work," says Zeisel.

Bignell even brought in a volunteer listener so that the residents would have more opportunities for one-on-one conversation. "The reason [we think] people with dementia don't know what's happening to them is because they don't vocalize it," says Tacke. "You have to spend time to get a response from them." Yet nursing homes tend to eliminate quality one-on-one time. "It's costly and time consuming," says Lisa Gwyther, a professor at Duke University Medical Center who directs the family support program at the Duke Aging Center, in which Butch's family participated. But, she says, "it's the ideal."

Bignell's efforts were transformative. "People could be themselves," says Plomp of the changed atmosphere at Hofwijck. Such results are echoed at the Green House homes and in other facilities taking similar innovative approaches to dementia care. Ortigara recalls the vivid transformation that people have undergone upon relocation to their house-like homes.

At her first Green House meal, a woman who had not been able to feed herself during her years at a standard facility "just took the spoon to start feeding herself, totally normally," says Ortigara. Afterward, she stood up for a spontaneous rendition of "Amazing Grace," a moment that still haunts Ortigara. "What would happen if we could just create normal places where people could use all of their remaining abilities?"

Even in traditional settings, recognizing the inner awareness of dementia patients has led to extraordinary results. At St. John Home, a highrise facility with 40 units per floor in Rochester, New York, geriatrician Allen Power reports an estimated 30% reduction in the use of drugs for managing dementia patients, which he attributes to the staff's growing ability to understand and listen to residents.

In *Dementia Beyond Drugs*, Power tells the story of Alex, who would act out every night after dinner—yelling, slamming drawers at the nurses' station and throwing things. It took a role-playing exercise—with a nurse pretending to be Alex—for the staff to realize that his seemingly nonsensical demands for "a line" were requests for a phone. Alex, it turned out, had been a traveling salesman and called his wife every night after dinner to tell her he loved her. The nurses began bringing Alex a phone after dinner. His tantrums stopped, and eventually he was taken off all medication. "Until they could get inside his head and look at the world through his eyes, no one could understand," says Power.

Not all Bignell's ideas have gone over so well. His plan to install a calendar with the correct year on it, for example, was met with strong resistance. The response may have been a reaction against "reality orientation," an outdated approach to dementia care in which facts were forced on delusional patients. Reality orientation was gradually replaced by "therapeutic fibs," which are also problematic since dementia sufferers are encouraged to remain in a delusional state.

Bignell thought the calendar offered a balanced, non-confrontational way to acknowledge residents' awareness. "The dominant medical view at the time said we have to allow them to be in the year in which they think they are," recalls Bignell. "But if you're aware, then you want to know what date it is, you want to know the weather, about world events." Ortigara agrees. "If that's a piece of information that's going to be useful, then they deserve that information."

Debates about calendars may seem relatively trivial. But little decisions like these actually reflect two very different approaches to understanding dementia. Are delusions merely erroneous perceptions or are they genuine but confused expressions of real feelings and needs? As Richard Taylor describes in *Inside Out*, if a dementia sufferer calls someone "Mom" or "Dad," they may not be confusing that person with their real mom or dad, who probably passed away long ago. They may instead be thinking about the feelings and behaviors they associate with their mom and dad. They miss those feelings. They may need those feelings. They may simply miss Mom and Dad.

A recent study published in the *Proceedings of the National Academy of Sciences* confirmed the persistence of these kinds of emotions, even when memories fade. After viewing film clips that evoked sadness, patients with severe amnesia continued to feel sad even when they could no longer recall the clip. Happiness-inducing segments yielded the same result. In *I'm Still Here*, Zeisel lays out the many types of memory—environmental, sensory, social norms, historical and others—that persist even when factual and sequence-based memories are gone. "All these memories are readily accessible to people living with Alzheimer's and their partners," he writes.

Studies like these suggest that the debate about how much awareness dementia sufferers have is far from over. Bignell laments how they are excluded from making decisions about their own care, even when they are able to voice opinions. "It's not easy to detect whether it's the person or the disease speaking," Bignell acknowledges. "But if you start by taking [them seriously], you might find out what their real needs are."

Bignell and a group of volunteers formed Springlevend in 2001 to promote this new model of care. In 2005, Hofwijck merged with three other homes and made Bignell manager of well-being for the entire network. He is now an independent financial advisor, while Springlevend engages with over dozens of retirement homes, offering memory and other workshops to help dementia sufferers and their families.

"If people are more aware than we think and are able to assess what they need, then we have to find ways to deal with that," Bignell says. The worst thing we can do, he says, is to cover it up. "What is absolutely prime with dementia is respect and safety and also that they know that we know." ■

JESSICA WAPNER *is working on remembering what's important and forgetting what isn't.*

Keep laughing...

...and nine other tips for partners, children and friends of those with dementia.

PHOTOGRAPH: OLIVIA AMES HOBLITZELLE

OLIVIA AMES HOBLITZELLE WAS 58 WHEN SHE HEARD that her husband, Harrison, had Alzheimer's disease. Harrison—"Hob" to friends—was 72. Suddenly, the Hoblitzelles had to rethink their plans for a carefree old age. The disease progression that followed was difficult. Years after her husband's death, Olivia is very clear about it: Alzheimer's is one of the worst illnesses there is, she says. It is disheartening, lengthy, exhausting and heartbreaking.

She wrote a compelling book about her husband's degeneration, *Ten Thousand Joys and Ten Thousand Sorrows*. In spite of everything, it is a book about love and life. Hob and Olivia decided early on that there was no point in clinging to their old life. The only way to deal with the last phase of Hob's life was to greet it with compassionate attention and love.

In her book, Hoblitzelle offers tips for partners, children and friends of the person with dementia. These are based in part on her experience as a psychotherapist and as a colleague of author and mindfulness training pioneer Jon Kabat-Zinn's.

MARIANNE LAMERS

1. **Accept the disease and the changes it brings with it, as frightening as they may be. It will help you tolerate the sadness..**
2. **Don't isolate yourself; instead, ask for help from family, friends, dementia organizations, spiritual counselors or therapists.**
3. **Remember the positive things you and the person with dementia had before in your relationship. Those loving moments form the thread that connects you.**
4. **Put yourself in the shoes of the person suffering from dementia. Imagine how upsetting it must be to lose so much. This openness and compassion will bind you to each other.**
5. **Find an outlet through which to express heavy emotions, such as frustration, anger and sorrow. It helps channel your feelings constructively.**
6. **It's true what they say: Keep laughing. Humor lightens the difficult moments.**
7. **Continue to involve the person with dementia in conversations, and realize that you are the one who must begin those conversations. Touch is one of the nicest ways to include someone.**
8. **Adjust your rhythm to that of the person with dementia. That will make things more restful for both of you.**
9. **Because someone with dementia constantly forgets things, it's important to be reassuring and validate him or her for doing things right.**
10. **Keep telling fun, positive stories from the past. You have become the guardian of his or her treasured history and memories.**

Find out more: *Ten Thousand Joys & Ten Thousand Sorrows: A Couple's Journey Through Alzheimer's*, by Olivia Ames Hoblitzelle (Tarcher)