

When Alzheimer's comes early

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Mary Kay Baum bends to photograph a woodland flower near her home at the Rock Ridge Cooperative in rural Dodgeville. She uses photography to help alleviate her symptoms of early-onset Alzheimer's disease that forced her early retirement as director of Madison-area Urban Ministry in 2006.

(Craig Schreiner -- State Journal)

Crouched on the budding forest carpet, camera in hand, Mary Kay Baum finds aid and comfort in a small white trillium. Centering her camera lens, she focuses on the flower, blocking out the world outside her 100-acre sylvan retreat at the Rock Ridge Cooperative farm near Dodgeville. This tiny, delicate trillium becomes a fellow warrior in Baum's fight against early-onset Alzheimer's disease.

"Meditation, for me, is walking in nature," Baum says. "And with photography I'm centering in on a scene or plant and the distraction of everything else around me fades away. I'm in the moment, in the place where I am."

When Baum announced more than two years ago that she was retiring as director of Madison-area Urban Ministry, many expected this firebrand of a public servant was bowing out of public life. Stepping down at age 58, she cited health concerns.

She was dealing with early-onset dementia. Feeling weak, depressed and unable to direct her staff, Baum felt she could no longer adequately perform her job.

Her announcement saddened many who watched Baum, as a lawyer and activist, champion such causes as American Indian rights, fair housing and prison inmates rejoining society. She fought for voices less-often heard as a two-term member of both the Dane County Board and the Madison School Board. She also ran for Madison mayor in 1987 and for state Assembly in 1992 as a member of the Labor-Farm Party.

Those who know her best could have predicted that Baum's struggles with early-onset Alzheimer's would simply direct her path toward a new crusade.

"This advocacy is a little more personal but with the same energy she's always given," says her sister Chris Baum VanRyzin. "She's always been an advocate. It's in her nature."

In this role, she's broken new ground as one of the first Alzheimer's patients in the country to sit on a local Alzheimer's board, seats usually held by care providers.

"Mary Kay being on our board puts us on the front-end of a trend," says Paul Rusk, executive director of Alzheimer's Association South Central Wisconsin chapter. "It's a great trend because this way they can tell us what they need."



Mary Kay Baum combines Western and Eastern medical approaches in developing a unique treatment regimen that she says has helped her multitude of symptoms from early-onset Alzheimer's improve over the past two years since she left the public limelight.

**(Craig Schreiner
-- State Journal)**

'Pulpit' in name

Digging among the plants, Baum finds a flower that delights her, but she can't instantly summon its name. "That's my main symptom now - not recalling words, especially when I'm tired" Baum says. "Pulpit. The name has pulpit."

It's not surprising this former nun turned Lutheran pastor comes up with that piece of the name of the gracefully curving jack-in-the-pulpit. She has cause to be tired because in her life's new ministry, reaching out to others affected by Alzheimer's, she spent the past few days networking at the statewide Alzheimer's Association conference.

"One of the biggest Alzheimer's symptoms that people don't know about is feeling overstimulated," Baum says. "For me now, being in a group where I don't know people, that exhausts me. It didn't used to exhaust me." Photography revives her. "I found that, instead of taking a nap after a gathering, I would go and be behind the lens, concentrate on the angle and my worries and concerns would leave. "

Baum noticed her symptoms early because they were familiar to her.

Long before she was diagnosed with probable Alzheimer's disease, she lived in its shadow, caring for her mother. Buelah Baum died 13 years ago at age 75, after living with the disease for 15 years. Baum's aunt also died of the disease. Her younger sister, Chris Baum VanRyzin, began experiencing what they now see as a family pattern of symptoms at age 41.

Shortly after Baum announced her retirement, she phoned Rusk, who directed her to his eight-week "Crossing Bridges" program. Little did he realize how strongly Baum would return that favor.



Mary Kay Baum found a new creative outlet in photography after developing symptoms from early-onset Alzheimer's. Focusing her lens on this woodland flower helps her center herself, blocking out the noise from the surrounding world.

**(Craig Schreiner
-- State Journal)**

Reminder of farm

While most of the flowers grow naturally on this nature preserve, Baum turns from photographing the jack-in-the-pulpit to a trout lily she planted here because it reminds her of the farm near Appleton where she grew up.

Although she uses photography for calm, creativity and focus rather than a memory aid, it serves the dual purpose. The lily sparks a tale from her family farm, just down the road from conservative, communist-hunting Sen. Joe McCarthy's farm.

"He's buried in the same cemetery as all my relatives," says Baum laughing at the irony. "Just going with the status quo was not so valued as living by your convictions in our community."

Among the only political traits Baum shares with McCarthy is her passion for her beliefs.

As a law student, she got involved in American Indian rights when there was a Menominee takeover of a novitiate in Shawano County — her home turf. As a School Board member she went to Arcatao, Madison's sister city in El Salvador, because the elected official who planned to represent Madison canceled at the last minute.

"All these things have fallen in my lap," Baum says. "The best I can say for myself is I've taken these opportunities and gone for them."

Although less welcome, Alzheimer's is also a cause that found her.

"I wouldn't have thought when I was running for mayor that I'd be advocating on a specific health issue," says Baum. "It doesn't seem all that radical. But it gets to the roots of our priorities as a country — the funding isn't there."

Baum counts herself as lucky because Alzheimer's often leaves people unable to work and financially devastated, but she has good disability insurance and is covered under a policy held by her husband, George Swamp, a social worker at Lincoln Elementary.

A pivotal event came in 2006 when she went to Washington, D.C., for the national Alzheimer's Association's policy meeting, where she lobbied lawmakers who told her they usually heard from caregivers.

"Most people in Congress have not had people talk to them who say, 'I have early onset Alzheimer's,'" Baum says. She also spoke at a national candlelight vigil on the steps of the Lincoln Memorial.

"When she spoke she stole the show," Rusk says. "We were so proud. Her work is incredibly important because it puts a face on the disease and it gets out our message that if you catch it early, life goes on ... maybe they can be like Mary Kay."

She continues public speaking, addressing Rotary clubs, church groups and other associations.

This fall, the Wisconsin chapter of the Alzheimer's Association plans to survey legislative candidates. "We want all the people running for state Legislature to tell us what they are going to do about this big epidemic that is coming," Rusk says. "And I have no doubt that Mary Kay will be our key contact person for the candidates. She's very persuasive."



Trillium, a spring forest flower, is a favorite subject of Mary Kay Baum who photographs and documents nature around her home on the Rock Ridge Cooperative Farm in rural Dodgeville.

(Craig Schreiner -- State Journal)

Beating dementia

Standing on the grass roof hill over her home that resembles a Hobbit burrow built into a hillside, Baum surveys the nearby woods in the Rock Ridge nature preserve. "I'm pretty steady," says Baum, taking a picture of the tree line. "For a time now I haven't used a tripod."

Rock Ridge is her retreat — far from city noise that would disturb her sleep in her former bustling East Side neighborhood. She recently became a full-time resident at the co-op and finds she no longer needs the 12 hours sleep she was taking after leaving her job. Friends have told her how happy they are to see her finishing her sentences now.

Baum and her sister Baum VanRyzin, who authored the book "Alzheimer's Averted: A Path to Survival," both make the rare claim among probable Alzheimer's patients — they've beaten back the dementia. They have taken charge of their own medical care, combining Western, Eastern and holistic medicine.

"I've actually improved," Baum says. "Both my sister and I have improved. It's not by one magic pill but by a multitude of things."

In addition to prescription medications, like the tremor-reducing Selegiline, she eats healthy and includes many vitamins and herbs, such as gotu kola, ginkgo and fish oil. She avoids MSG and artificial sweeteners. And she does hand exercises and CranioSacral therapy, a form of massage, to stimulate circulation.

Baum knows her belief in improvement is greeted with medical skepticism: "There are some doctors who would say to me that I can't have Alzheimer's because you can't improve — you're just doing too well."

Dr. Sanjay Asthana, head of geriatrics at the UW School of Medicine and Public Health and associate director of the Wisconsin Alzheimer's Institute, explains that while in biological terms the disease cannot improve, symptoms can be stabilized and improve for a time.

Currently an Alzheimer's diagnosis is considered probable, because it cannot be given with certainty until a person dies and an autopsy has been performed.

"Go to a physician as early as possible," recommends Asthana. "It's important to diagnose the disease as early as possible, even before there are symptoms," because that's when treatment to slow Alzheimer's progression is most effective.

Baum's mother also experimented with various treatments. "I believe it was for the sake of us," Baum says. She and her sister are now doing the same, not only for themselves and their children (Baum has an adult son and daughter), but also to share what they find that works as broadly as possible among early-onset patients.

This was another way her D.C. trip helped — she and her sister sought out other early-onset patients. They met, compared notes, exchanged e-mails and found mutual symptoms people don't always associate with Alzheimer's like bodyaches, lack of coordination or fatigue. Helped by these conversations, they banded together to form a nonprofit group they named "forMemory."

They are now documenting their symptoms and what helps in a database to share with other patients and doctors.

And forMemory is now linked to Baum's photography. She recently published a book, "Crossing Bridges with Hope: Sharing Our Experiences with Early-Onset Dementia," that includes her photos. All proceeds benefit forMemory.

Finding a new creative outlet after an Alzheimer's diagnosis is common, says Baum, who had never taken photos other than snapshots previously. In finding a new kind of life, she's finding hope.

"I think it's important that people face their losses. I suggest that as a form of pastoral care," Baum says. "But then move on to the hopefulness."

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Direct and indirect costs of Alzheimer's will rise

Alzheimer's is a disease of the brain that causes problems with memory, thinking and behavior and is the seventh leading cause of death, according to the Alzheimer's Association.

The group's 2008 statistical report says up to 5.2 million people in the United States have Alzheimer's disease and its direct and indirect costs to Medicare, Medicaid and businesses is more than \$148 billion each year.

These numbers only stand to rise.

"There are so many baby boomers coming down the pike and new statistics say that 18 percent of them will eventually develop Alzheimer's disease and that will overwhelm the health care system," says Paul Rusk, executive director of the Alzheimer's Association South Central Wisconsin Chapter. "We're trying to push Congress to respond to that and increase funding, which has been flat for the last few years."

On May 14, the Senate Special Committee on Aging, co-chaired by Wisconsin Sen. Herb Kohl, held a hearing on the burden Alzheimer's poses to those living with the fatal disease, their caregivers and the health care system. Former Supreme Court justice Sandra Day O'Connor and former house speaker Newt Gingrich testified in favor of increased research funding for the disease.

This push for research could benefit the UW-Madison.

Over the past five years, says Dr. Sanjay Asthana, associate director of the Wisconsin Alzheimer's Institute and the head of geriatrics at the UW School of Medicine and Public Health, "the University has made it a mission to do Alzheimer's research (developing) a very well-funded and well-reputed program." The program has attracted \$27.8 million in research grants. Two weeks ago, the UW Medical School - along with the state, the Veterans Hospital and the Helen Bader Foundation - applied for \$8.8 million from the National Institutes of Health (NIH) to open a Wisconsin Alzheimer's Disease Research Center. They expect to hear results by November.

UW-Madison is involved in 41 ongoing Alzheimer's studies, not only researching potential treatments and cures, but also looking to diagnosis Alzheimer's before symptoms occur using such methods as brain scans, genetic tests and locating an abnormal protein associated with the disease, says Asthana. "People usually have the disease 20 to 25, maybe even 30 years before the symptoms."

Another Alzheimer's project is the Wisconsin Registry for Alzheimer's Prevention (WRAP), headed by Dr. Mark Sager, director of the Wisconsin Alzheimer's Institute, that has registered and is conducting a 15-year study of 1,200 people, most of whom had parents with Alzheimer's.

"This is one of the most costly diseases to treat," Asthana says. "In this country 13 percent of people over 65 have Alzheimer's and over the next 20 years that number will be 20 percent. It's important that our major areas of research are diagnosing the disease as early as possible and finding effective treatments and one day a cure. It's still a dream, but now a very achievable one."

— *Melanie Conklin*

For more information or questions

For more information about warning signs of dementia, local memory diagnostic clinics, or any questions, contact:

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