

## **A cruel disease, a family in crisis**

For any family, Alzheimer's disease is a cruel diagnosis.

The disease attacks the brain, erasing memory, destroying the ability to reason and leading inexorably to the disintegration of the personality and a pitiless death. There is no cure.

But what Mary Dyer's family endured — emotionally, logistically, financially — after the popular Evergreen Public Schools elementary school counselor developed early-onset Alzheimer's at 55 added another layer of cruelty.

The safety net Mary Dyer and her husband Arnie thought they had created for themselves during their long careers as educators failed them in the final four, desperate years of Mary's life.

After her diagnosis in 2003, when she could no longer work, her insurance company denied Mary Dyer's claim for coverage on grounds that her Alzheimer's was a pre-existing condition.

She was too young to qualify for Medicare coverage, which normally kicks in at 65. So Arnie Dyer paid out of pocket for her health insurance and the cost of her care — costs that reached nearly \$100,000 by the time of her death in September 2006.

Mary Dyer spent the last 14 months of her life in a state-licensed family home, being cared for by strangers, at a cost that climbed to \$2,500 a month. Her exhausted family thought she might live for 10 more years, needing around-the-clock custodial care.

"Even in August, she was highly active," Arnie Dyer said. "I was thinking that she could go on for a long time."

Dyer, a teacher at Evergreen High School, still struggles with guilt about turning over his wife's care to others.

"It's the worst decision I've ever made in my life," he said. "How does someone make a decision like that? Had I known she would have a relatively short illness, I might have made other decisions. I could have brought in a full-time nurse. "

At the advice of an attorney, Arnie Dyer filed for a legal separation from his wife of 35 years and cashed out her retirement in an attempt to qualify her for Medicaid, the federal-state health insurance plan for the poor.

Mary Dyer died at 60. At her death, she still had not qualified for Medicaid or Medicare.

“These are people who had paid into the system for years,” said the Dyers’ 35-year-old daughter, Kate Dyer-Seeley. “It’s an ethical issue. People shouldn’t have to go bankrupt to get medical care.”

### **Government regulations**

Since 1972, Congress has required a two-year waiting period before severely disabled people younger than 65 can begin receiving Medicare coverage. First they must qualify for Social Security disability insurance, a lengthy process in itself. Then they must draw those benefits for 24 months.

The waiting period was instituted to prevent people from shifting from private insurance plans to Medicare before they retired at 65. But the waiting period leaves about 400,000 disabled Americans uninsured or underinsured at a time when they are in urgent need of health care. In 2007, the prestigious Institute of Medicine recommended that Congress reduce or eliminate the 24-month wait.

Bills introduced in both the House and the Senate last year would phase out the waiting period over 10 years at a cost of \$8.7 billion annually. That cost would be partially offset by \$4.3 billion annually in Medicaid savings.

In the meantime, the legislation would create a process by which those with life-threatening diseases like Alzheimer’s could get an exception to the waiting period. Already, Congress has waived the wait for victims of Lou Gehrig’s disease and those with end-stage kidney failure.

In May, Kate Dyer-Seeley traveled to Washington, D.C., to meet with the Washington congressional delegation and lobby on behalf of the Ending the Medicare Disability Waiting Period Act of 2007.

The bill is sponsored in the Senate by Sen. Jeff Bingaman, D-New Mexico, and in the House by Rep. Gene Green, D-Texas.

She told the story of her mother’s last years and her family’s ordeal.

“I had to do a lot of educating,” she said. “A lot of people were reluctant to commit. They asked, ‘Why should this be a priority?’”

Her answer: “The epidemic that is coming is unprecedented. We found money to research bird flu, something that never reached the shores of our country.”

So far, Sen. Maria Cantwell, a Democrat, is the only member of the Washington delegation who has signed on as a sponsor.

Scores of organizations representing victims of cancer, AIDS, cerebral palsy, epilepsy and many other life-threatening diseases support the legislation. But the Alzheimer's Association makes a particularly compelling case.

An estimated 500,000 Americans younger than 65 have early-onset Alzheimer's or related dementia. They constitute 10 percent of all Alzheimer's patients, and most might eventually qualify for Medicare benefits under Social Security disability rules. But the association says the waiting period is so long that it can bankrupt families as they watch their loved one regress, needing more and more services.

The number of people with Alzheimer's is expected to hit 16 million by mid-century, more than triple the current total. And experts say more of those victims will be younger than 65 — still working and active until the progressive disease robs them of everything.

"We realize this is not going to be passed this year," said Brenda Sulick of the Alzheimer's Association. "Our focus has been educating people about this issue. Should we have a broader health care debate in coming years, we hope this will be on the table."

Other bills introduced in Congress would provide a tax credit to those who must pay for care of Alzheimer's patients, allow employees to use accrued sick leave to care for a relative with Alzheimer's, and expand caregiver respite and support services, including the services of social workers to contact insurance companies and state and federal agencies and cut through the bewildering tangle of red tape.

That's help that is desperately needed, Arnie Dyer said. "Most people just stumble in the dark. We had lots of resources, the kids were great, but at the time you're so overwhelmed."

At the state level, Dyer-Seeley hopes the Legislature will create an Alzheimer's task force and provide more support for in-home care.

She has also written to all the presidential candidates, asking them to support the federal legislation.

"It's important we look at this as a nonpartisan issue," she said. "Your voter registration card does not protect you from getting Alzheimer's."

## **A life cut short**

Mary Dyer was an exuberant, outgoing woman. She was dedicated to her work as an elementary school counselor in the Evergreen district, a program she pioneered. When she began forgetting where she had put her eyeglasses, and struggled with a new computer program, her family at first put it down to menopause or mild depression.

She changed jobs in the late 1990s, moving to Vancouver Public Schools to work with high school students, then returned to Evergreen in 2001. Soon after, her condition deteriorated and she left her job.

In 2003, after she was diagnosed with Alzheimer's, Arnie Dyer found a place for her in a Vancouver adult day care center.

"We pitched the day care center as someplace she could volunteer and help others," Dyer-Seeley said. "She could fake it so well. She was so socially adept. People would say, 'She looks great!' But she couldn't write her name; she couldn't tell you what year it was."

The family never used the word Alzheimer's around Mary. "She understood what it meant," Dyer-Seeley said. "We spoke in code. We would say, 'My mom has cognitive delay.'"

A crisis unfolded when the day care center, hit by a change in a state funding formula, reduced its days of operation. Arnie Dyer hired nursing students at Clark College to stay with his wife two days a week while he taught school.

"As difficult as the expense was, just finding someone to come into the house was a huge challenge," he said. "She needed someone to be around to make sure she didn't wander away, to make sure she ate."

As time went on, Mary became incontinent. She began staying awake at night, experiencing increased agitation and paranoia.

"We started realizing that this is beyond what we can handle," Dyer-Seeley said. By then she was the mother of a newborn son. "This is a time when she is supposed to be teaching me to be a mom. Instead, I was caring for my mom."

That's when the Dyer family made the wrenching decision to place Mary in a state-licensed home.

The couple who ran the home cared for their own two young children and two other clients. Even near the end, Mary took pleasure in being around young children.

“Professionals tell you you’ll know when it’s time,” Arnie Dyer said. “A piece of advice I would give would be to discuss this while you can still have a rational discussion.”

Two years after Mary Dyer’s death, the sadness lingers. “These were the years we were going to prepare for retirement, take trips,” Arnie Dyer said.

Kate Dyer-Seeley says she sometimes feels that she is channeling her mother’s energy. It helps fill the void.

“My mom was the big spoke missing in the wheel.”

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