

# National Alzheimer's Project Act (NAPA)

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The information that follows was included as an attachment to an email submitted by the public.

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<http://aspe.hhs.gov/national-alzheimers-project-act>

# Down syndrome and Alzheimer's: A double burden



*Marilyn Long talks about the challenges involved with taking care of her brother, Jeff Malanoski, who has Down syndrome and has also recently been diagnosed with Alzheimer's disease.*

By [Barbara Brotman](#), Tribune reporter [contact the reporter](#)  
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People with Down syndrome are living longer, and more are getting Alzheimer's; Support group tries to help

Jeff Malanoski sat in front of his bowl of cereal, watching "The Price is Right" and forgetting to eat his breakfast.

His sister, Marilyn Long, sat at the table next to him and repeatedly reminded him.

"Why don't you eat your cereal?" she coaxed, reaching over his shoulder to give it a stir.

Her husband, Mike Long, sighed.

"It takes forever," he said.

It didn't used to. Malanoski has Down syndrome, but until a few years ago, he ate without prompting, dressed himself and was relatively easy for the Longs to care for in their Elk Grove Village home, as they have for 26 years. For 20 years, he worked as a bagger at Jewel.

Now, however, his sweet smile is topped by short gray hair. He can't eat or dress by himself. He no longer works; he was forgetting how to bag groceries. He no longer knows how to tie his shoes.



Marilyn Long and Jeff Malanoski  
Chris Walker / Chicago Tribune

Marilyn Long gives some medication to her brother, Jeff Malanoski, 57, during breakfast. Long and her husband, Mike, far left, take care of Jeff, who was born with Down Syndrome and has now developed Alzheimer's.

Malanoski, 57, lives with a neurological double-whammy: In addition to Down syndrome, he has Alzheimer's disease.

The two conditions are genetically linked. Even so, the combination was rarely seen years ago because people with Down syndrome usually didn't live long enough to develop Alzheimer's and other illnesses of aging.

But now medical advances have extended the life expectancy of people with Down syndrome, and families are encountering the reality spelled out in figures from the **National Task Group on Intellectual Disabilities and Dementia Practices**:

Adults with Down syndrome are at high risk for developing Alzheimer's disease, and at an earlier age than the population as a whole. At least 25 percent of those older than 40 have Alzheimer's, and more than 50 percent of those over 60 do, compared with 6 percent of those over 60 in the overall population. The Adult Down Syndrome Center at Advocate Lutheran General Hospital has been seeing so many families struggling to care for people with Alzheimer's that it recently started a support group, which is believed to be the only one in the country.

"It's clear that our patients are not just the patients, but the family trying to deal with it," said **Dr. Brian Chicoine**, the center's medical director.

At the group's second meeting this month, family members sat in a circle and went around the room, describing the increasing toll Alzheimer's is taking.

"She doesn't know her numbers now," said Marian Harrington, whose daughter is 55.

"I was in shock; she could not write her last name," said Meg Kerber, whose sister is 54. "The letters threw her, even when I told her it was a 'B.'"

"I have to dress him. I have to make sure he eats," said Marilyn Long. "He doesn't even know how to change the TV (channel) anymore — and he used to do all that.

"He's losing the ability to do everything he worked so hard to do."

That seemed to encapsulate the sadness around the room. The skills being lost to Alzheimer's were hard-won. The disease was upsetting decades of carefully arranged services and living arrangements. "He's forgetting how to do things that it took him 50 years to learn," said Bill Zermuehlen, father of 50-year-old Chris.

People with Down syndrome have an extra copy of the 21st chromosome, which carries a gene that produces one of the key proteins behind the changes in the brain characteristic of Alzheimer's.

The protein, beta-amyloid, damages brain cells and forms amyloid plaques, a hallmark of Alzheimer's disease, said **Dr. Michael Rafii**, director of the Adult Down Syndrome Clinic at the University of California at San Diego and a key researcher in the field.

And because people with Down syndrome have an extra copy of the 21st chromosome, he said, they overproduce beta-amyloid.

By age 40, everyone with Down syndrome has the neurological pathology — plaques and tangles, which are twisted strands of another protein — characteristic of Alzheimer's. Some start developing the plaques by age 12, Rafii said.

That doesn't mean they will inevitably develop Alzheimer's, he said; 30 percent of people in the general population over age 65 have plaques but no memory problems.

"But having plaques does indicate a very high risk of progressing to dementia," Rafii said.

Researchers are studying people with Down syndrome in hopes of gaining insight into Alzheimer's that could be widely useful, he said. "Understanding how Alzheimer's disease develops in (people with) Down syndrome will hopefully not only benefit people with Down syndrome, but also the population as a whole."



Chris Walker / Chicago Tribune

*Jeff Malanoski, 57, brushes his teeth in his own bathroom in his Elk Grove Village home. Jeff's sister, Marilyn Long, and her husband, Mike Long, take care of Jeff.*

The disease is largely the same — and as individually variable — for people with Down syndrome as it is for everyone else. However, it appears earlier, with an average onset age of 52, according to the national task group. In the population as a whole, most people are diagnosed at 65 or older.

And there are other differences. "When it does hit people with Down syndrome, it tends to go a little faster," said **Tamar Heller**, director of the Institute on Disability and Human Development at the University of Illinois at Chicago, a major sponsor of the national task group.

People with Down syndrome die of Alzheimer's in an average of five to eight years, compared with seven to 20 years for the population as a whole, according to the task group.

"And it's very hard to diagnose," Heller said. "It's hard to tell (if there has been memory loss) when someone already had impairments related to memory and cognitive disabilities."

The outgoing, friendly demeanor of someone with Down syndrome often changes when Alzheimer's sets in, said **Matthew Janicki**, co-chairman of the national task group.

"The personality becomes more blunted," he said. "There's less outgoingness, more withdrawal, anxiety, depression."

They may become agitated or aggressive, Chicoine said, posing serious problems for families.

"We're looking at a man or woman in their 50s being cared for by an 87-year-old parent," he said. "That's a significant challenge."

Many families never imagined they would have to deal with illnesses of aging. Marian Harrington recalled that when her daughter was born, the doctor estimated that she would live to age 12.

And in a particularly cruel twist of fate, elderly parents taking care of a child with Down syndrome and Alzheimer's may develop Alzheimer's themselves.

"Sometimes we see a sibling trying to deal with a parent and a sibling with Down syndrome, both with Alzheimer's, at the same time," Chicoine said.

"It causes a really huge problem for the support network," said **Dr. Seth Keller**, the other co-chairman of the national task group.

Agencies that provide help for the developmentally disabled are also scrambling to provide help for Alzheimer's and other illnesses of aging.

"There's a lot of strain put upon organizations," he said. "They need resources. They need to bring in support staff."

Chicago's Misericordia is building four new houses for aging residents, including people with Down syndrome who came to live there as children, said Executive Director Sister Rosemary Connelly. It will offer programs for those with advanced Alzheimer's.

The onset of Alzheimer's sometimes forces families to change living arrangements.



Chris Walker / Chicago Tribune

*Marilyn Long encourages her brother to eat his breakfast.*

Mary and Jonathan Heggen moved Jonathan's 56-year-old sister, Maribeth, from the supported living facility in Morris, where she had been for more than 30 years, to a Park Ridge nursing home.

Though it turned out to be a happy move, "it was gut-wrenching for us," Mary Heggen said.

And it hadn't been easy to find a nursing home that would take her. At one that the Heggens had called, "they were very leery of even considering someone with Down's," she said, "even though I said, really, at this point it's much more the Alzheimer's."

Bill and Cara Zermuehlen are planning to bring their son home. They recently lost state funding for one-on-one care several hours a day, and without it they think it is unsafe for him to stay in his group home, where he has roommates he has known since grade school.

"It's going to be hard on Chris and on his roommates," Bill Zermuehlen said.

It won't be easy on them, either. Chris has lost the ability to walk, talk and swallow, and Bill and Cara are in their 70s.

But they have sold their home and rented a first-floor condo to give it a try.

The discussion at the support group turned to medications for anxiety, legal guardianship, nursing home recommendations — and the perplexing question of whether people with Down syndrome are aware that their cognitive abilities, already compromised, are being stolen by Alzheimer's.

"I think he realizes something is the matter, but he doesn't know what the matter is," Cara Zermuehlen said. "He has this look on his face like, 'Where am I? What am I doing?'"

The Longs have seen similar expressions. At their home, Marilyn Long gave her brother his day's pills to swallow. Moments later, he pointed to his mouth, asking for his pills.

[cComments](#)

- *Thank you Ms. Brotman for a touching article. It puts flesh and bones on the numbers and lovingly captures the heartbreak of caring for a Down Syndrome person with dementia. The video which accompanies the article perfectly captures his sweet, sweet soul.*

*mmurphy19*

*at 2:17 PM September 25, 2014*

"I already gave them to you, remember?" she said.

He put his hand on his forehead and shook his head in frustration.

He knows when he forgets something, the Longs say, and shows it.

Marilyn Long squeezed toothpaste onto his toothbrush. She handed him clothes to put on. She was taking him with her to bring her grandson to the dentist because she doesn't dare leave him in the house alone.

"This is probably the hardest thing I've ever had to do," she said. "You have to give up so much of your life."

Her husband, who is at work every day, is concerned about the increasing burden on his wife. But she is determined to keep Jeff at home, possibly with the help of an aide. As for a nursing home, "the day he doesn't know who I am — then, maybe," she said.

"But I would be there all the time."

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