

# Honored, but reluctantly



THE COLUMN

Joye Brown

joye.brown@newsday.com

It was an honor Karen Henley wishes she never had to accept.

When she found out she had been named the 2011 Frank Carlino Outstanding Advocate by the Coalition of New York State Alzheimer's Association chapters, she simply cried.

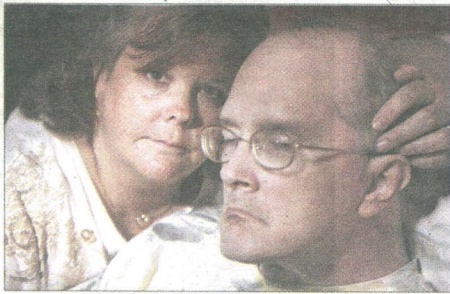
"I was sitting next to you," daughter Courtney chimed in. "You said, 'There shouldn't have to be an award for this.'"

She was honored, of course. Her children beamed as she accepted the award in Albany last week. It's just that she wishes no one had to be an advocate for a cure.

Henley's husband, Mike, once a successful salesman, was diagnosed with early onset Alzheimer's 10 years ago, at the age of 36. The family's struggle to care for him at home was featured in Newsday's 2009 series, "Alzheimer's: The Love and the Heartbreak."

Since then, Karen Henley — who described herself as once so shy she wouldn't get up to speak in class — has traveled the nation to press for research dollars toward an Alzheimer's cure.

Now 50, she still works for a real estate lawyer. The couple's children are making plans of their own. Courtney, who wants to be a filmmaker, is now at Fordham University; and son Brandon is trying to decide whether he wants to study physical therapy at Seton Hall



Karen Henley has become a leading advocate of research for a cure for Alzheimer's, which affects her husband, Mike.

NEWSDAY FILE PHOTO / T. CONRAD WILLIAMS JR.

**NOW ONLINE** See photos of Mike Henley, and glimpse the tremendous love and attention given to him by his family. [newsday.com/li](http://newsday.com/li)

or Quinnipiac after his June high school graduation.

What has not changed is the family's commitment to caring for Mike Henley, who cannot speak or move around, and who needs 24-hour care at home.

It's extraordinarily hard, and getting harder.

After traveling to Albany to receive her award, Karen Henley was back to Westbury that evening, back to feeding and clothing and changing and moving her husband of 23 years between a special chair and the hospital bed where she still squeezes in beside him each night.

And there was also the latest obstacle for the family, the latest pull on what Henley acknowledges are her already

wrecked finances.

Under a state formula, Henley is responsible for about \$1,200 a month in home care health-related expenses not covered by Mike Henley's disability and other payments.

"You go from a high in Albany and come back to the low of the reality of fighting to give Mike what he needs at home," she said.

And then she repeated the lament of caregivers who choose to keep their loved ones home.

"We save the system money because we provide the nursing care, we're here in the middle of the night, we're here in the morning to get breakfast together," she said.

"Why does it have to be so hard? Why are there so many things to get through when all I

want to do is take care of my husband?" she said.

She said she has received some suggestions on how to resolve the problem. And, through the Long Island Chapter of the Alzheimer's Association, she said, she's also receiving support.

As it is, Henley has no health care insurance for herself. She said it was canceled because she could not pay the bill. She also has asthma and a thyroid condition, she said, but has stopped taking her regular medication for both because she can't afford those either.

"I used to be a meticulous, organized person," she said. "Now, bills stack up and I don't get to what I want to do. Everything is overwhelming, it's just overwhelming."

And yet she will keep on working, keep on advocating to bring money, resources and more attention to Alzheimer's.

"I don't want anybody to have to go through all of this," she said. "You do what you've got to do, but it shouldn't have to be so hard."

Through it all, Mike Henley — who was once so calm, so strong — remains the center of the family's attention. Karen Henley often leaves the television in the living room on a station playing hits from the 1980s.

"That's from our time," she said wistfully, as Phil Collins, sang "In the Air Tonight" in the background.

"Mike loves it when the drums come in," Henley said, reaching over to pull back a few strands of thinning hair from his head. "Don't you, babe?"

Sometime later, his eyes pull open. They are an incredible shade of blue.