

## Rising Alzheimer's creates strain on caregivers

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WASHINGTON (AP) — David Hilfiker knows what's coming. He was diagnosed with Alzheimer's so early that he's had time to tell his family what he wants to happen once forgetfulness turns incapacitating.

"When it's time to put me in an institution, don't have me at home and destroy your own life," said the retired physician, who is still well enough that he blogs about the insidious progress of the disease. "Watching the Lights Go Out," it's titled.

Nearly half of all seniors who need some form of long-term care — from help at home to full-time care in a facility — have dementia, the World Alzheimer Report said Thursday. It's a staggering problem as the global population ages, placing enormous strain on families who provide the bulk of that care at least early on, and on national economies alike.

Indeed, cognitive impairment is the strongest predictor of who will move into a care facility within the next two years, 7.5 times more likely than people with cancer, heart disease or other chronic ailments of older adults, the report found.

"It's astonishing," said Marc Wortmann, executive director of Alzheimer's Disease International, which commissioned the report and focused on the problems of caregiving. "What many countries try to do is keep people away from care homes because they say that's cheaper. Yes it's cheaper for the government or the health system, but it's not always the best solution."

And dropping birth rates mean there are fewer children in families to take care of aging parents, too, said Michael Hodin of the Global Coalition on Aging.

"Very shortly there will be more of us over 60 than under 15," he noted.

Today, more than 35 million people worldwide, including 5 million in the U.S., are estimated to have Alzheimer's. Barring a medical breakthrough, those numbers are expected to more than double by 2050.

This week, the U.S. National Institutes of Health announced \$45 million in new Alzheimer's research, with most of the money focused on finding ways to prevent or at least delay the devastating disease. The Obama administration had hoped to invest \$100 million in new Alzheimer's research this year, a move blocked by the budget cuts known as the sequester. Overall, the nation has been investing about \$400 million a year in Alzheimer's research.

But the disease's financial toll is \$200 billion a year in the U.S. alone, a tab expected to pass \$1 trillion

by 2050 in medical and nursing home expenditures — not counting unpaid family caregiving. The world report puts the global cost at \$604 billion.

Thursday, families affected by Alzheimer's and aging advocates said it's time for a global push to end the brain disease, just like the world's governments and researchers came together to turn the AIDS virus from a death sentence into a chronic disease.

"We need a war on Alzheimer's," said Sandy Halperin, 63, of Tallahassee, Fla., who was diagnosed with early-stage Alzheimer's three years ago. He now finds himself stumbling for words, but still visits lawmakers to urge more funding.

Meanwhile, the world report focuses on caregiving, stressing how the needs of people with dementia are so different than those of other ailments of aging, such as cancer and heart disease. People with dementia begin needing some help to get through the day early on, to make sure they don't leave the stove on or get lost, for example. Eventually, patients lose the ability to do the simplest activities of daily life, and can survive that way for a decade or more. Often family members quit their jobs so they can provide round-the-clock care, and the stress can harm their own health.

The world report said families need early education about what services are available to help before they're in a crisis, plus training in how to handle the behavioral problems of the disease — such as not to argue if their loved one thinks Ronald Reagan is still president, or how to handle the agitation at dusk known as sundowning, or how to react when the patient hits someone.

Two-thirds of the calls that Home Instead Senior Care, which provides in-home personal care services, receives are from families that did no planning until the patient had a crisis, such as wandering or a fall, said its president, Jeff Huber.

Hilfiker, the blogger with early Alzheimer's, takes that education idea a step further. He tells everyone he knows that he has Alzheimer's as a way to break some of the stigma, "so when I make dumb mistakes, I don't need to be embarrassed," he said Thursday.

He urges other patients to plan their end-of-life care early, while they're still cognitively able to participate. He believes that telling his wife no extraordinary care — no feeding tubes, for example — will ease her burden.

Hilfiker's big unanswered question: "If I'm at peace with my disease, does that make it easier to care for me later?"