



# Living With Alzheimer's Before a Window Closes

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Sally Ryan for The New York Times

Lawrence Goldstein, center, and Mollie Simon on the Culture Bus, a Chicago Alzheimer's support group.

By JANE GROSS  
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Mary Blake Carver gazes from the cover of a neurology magazine this month, under the headline "I'm Still Here!" She often feels like shouting the message to her friends, her children, her husband.

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*Some organizations, social service agencies and research counseling projects that assist those with early stage Alzheimer's disease.*

- Alzheimer's Association,**  
312-335-8700  
24 hour helpline: 800-272-3900.
- New York City chapter,** 800-272-3900
- Northern California chapter,** 650-962-8111
- Oklahoma City chapter,** 405-319-0780 or 918-481-7745

**Northwestern University Alzheimer's Disease Center**

**Council for the Jewish Elderly**

Ms. Carver, 55, is among the growing ranks of people in the early stages of [Alzheimer's](#) disease, when short-term memory is patchy, organizational skills fail, attention wanders and initiative comes and goes. But there is still a window of opportunity — maybe one year, maybe five — to reason, communicate and go about her life with a bit of help from those around her.

Yet Ms. Carver is often lonely and bored. Her husband leaves her out of many dinner table conversations, both say, because she cannot keep up with the normal patter. He insists on buttoning her coat when she fumbles at the task. She was fired as a massage therapist because she lost track of time. So Ms. Carver fills her days by walking her neighborhood on the Upper West Side of Manhattan, always with her dog, so she looks like "an ordinary person," she said, not someone with "nothing better to do."

Five million people in the United States have Alzheimer's disease, according to a study last week by the Alzheimer's Association. About half, 2.5 million, are at the early stages of the disease, other studies have found, struggling to pass

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For info on Northwestern's early stage support groups, contact Andrea Skoglund at 312-503-0604. For info on Northwestern/Council for Jewish Elderly culture bus, contact Judy Holstein at 847-492-1400 or Andrea Skoglund.

To enroll in N.Y.U. couples and caretakers studies, contact Olanta Barton at 212-263-5710, Cynthia Epstein at 212-263-1056 or Ursula Auclair at 212-263-2245. Web site: [N.Y.U. Alzheimer's Disease Center](#)

[Family Caregiver Alliance](#), 800-445-8106

[The Alzheimer's Disease Education and Referral Center \(ADEAR\)](#), 1-800-438-4380

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Paulette Michaud, manager of early stage services at the New York City Alzheimer's Association chapter, standing at right, next to Stephen Carver, whose wife, Mary Blake Carver, 55, seated at left, has early Alzheimer's, as do John Carpenter, 82, center, and George W. Rapoport, 67.

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life.”

Absent a cure, or more effective drugs, Alzheimer's disease is a march to oblivion. But the process can unfold over two decades. Patients at the front end, said Paulette Michaud, manager of early stage services at the New York City Alzheimer's Association chapter, “lose the sense of independence and control much more quickly than they need to because everyone focuses on their deficits.”

“These are still viable people,” Ms. Michaud continued. “What are they supposed to do

for normal.

They are impaired but not helpless or demented, and now a growing number are speaking out about how it feels to be them: Silenced prematurely or excluded from decision making. Bristling at well-meaning loved ones who boss them around. Seeking meaningful activities to fill their days.

Out of their individual frustrations, these patients are creating a grass-roots movement to improve services and change public perceptions. And they are making a mark.

Early stage patients like Ms. Carver, telling their own stories, have become popular speakers at national conferences and persuasive lobbyists with state and federal lawmakers. Closer to home, they are pushing for more patient support groups, creating social networks and taking part in couples counseling to restructure their marriages after diagnosis.

Rarely have ill spouses and well spouses participated in joint support groups because of the widespread belief that their fears and frustrations are very different and that Alzheimer's patients were too far gone to benefit. Historically, social service agencies have focused on the needs of caregivers. But that, too, is changing. “We've given wide attention to the caregivers and ignored the psychological and relational aspects of the lives of people with the disease,” said Peter V. Rabins, a professor of psychiatry at the [Johns Hopkins University](#) and a co-author of “The 36-Hour Day,” a guidebook for caretakers. “So these are important steps toward redressing this imbalance.”

Ms. Carver's husband, Stephen, an electrician at a Broadway theater, is mindful that spouses — fearful and overwhelmed — can be insensitive and impatient as their mates' abilities decline.

“They can't always follow what's going on if there's too much input,” Mr. Carver said. “Their brains have to work so much harder, which tires them out, and their logic isn't always linear, so there's a tendency to think they don't comprehend. I'm not a patient person by nature, and Mary's losing her mental capabilities. So I have to slow down and adapt. And I have to remind myself that she still has feelings and perceptions. She still has an emotional



Peter DaSilva for The New York Times

Peter Hebert, 67, of San Anselmo, Calif., who was found to have early signs of Alzheimer's in 2002, advocates for patients in Northern California.

for the next three, four, five years of life?"

Some answers are emerging, as patients request and help design new programs at academic medical centers and social service agencies. Among them is a speakers' bureau at the New York City chapter of the Alzheimer Association that grew out of complaints of boredom.

Ms. Carver is among the most popular speakers. She flushes with accomplishment when she is on the podium at a conference but recalls none of it moments after leaving the stage. Ms. Carver sobs at the extent of her short-term memory loss. Her support group friends comfort her, reminding her that their memories may be better, but their speech or concentration is worse.

At the Alzheimer's clinic at [Northwestern University Medical School](#), support group participants told Darby Morhardt, the facilitator, that they yearned to spend more time together. As a result, in partnership with the Council for the Jewish Elderly in Chicago, Ms. Morhardt's support group takes regular bus trips to historical and cultural sites of their choosing like an African-American art museum, a glass blower's studio and a Hindu temple.

Social groups are also springing up for couples. In San Anselmo, Calif., Peter and Judy Hebert regularly entertain new friends from Mr. Hebert's two support groups, each with different deficits but all relatively high-functioning.

Mr. Hebert, once an official at the [General Services Administration](#), is 67 and retains his short-term memory, but his speech and motor skills are deteriorating five years after diagnosis, and he cannot reassemble a sandwich should one piece of bread fall off. But he can maintain a busy schedule visiting assisted-living centers and nursing homes to exhibit his landscape photography, and sometimes his speech flows.

"It feels like I'm working," Mr. Hebert said.

His wife accompanies him, struggling not to fill in the blanks in his halting sentences.

"We all have that tendency to take over," she said.

How much hovering is too much has been a common topic in couples counseling sessions at [New York University](#) that are part of a research study by Dr. Mary S. Mittelman.

The study, in which couples receive six counseling sessions together, was to have included 200 couples, but 16 have signed up, an indication, some of Dr. Mittelman's colleagues said, that many couples still do not welcome frankness.

At the sessions, a counselor with expertise in Alzheimer's disease can guide the conversation, slow everything down and offer enough encouragement so the ill spouse can participate. In reviewing early results, Dr. Mittelman said, the patients with dementia said they enjoyed being included, and their spouses said they learned ways to make that happen.

Months later, the patients remembered the counselor and were happy to be back, though the content of the sessions had disappeared from memory and they veered between confusion and understanding.

"What am I doing now?" asked John McCrosky, 75, directing the question at his wife, Corinne Samios.

The counselor intervened, asking, "Are you the same John as when I saw you last?"

"No, I'm not the same," he said, slyly setting up the punch line to his own joke. "Now I can't remember to flush."

The second study involving couples, led by Carol J. Whitlatch of the Cleveland Institute, compared the expectations of the ill spouse and the caregiver spouse, with an eye toward planning for the future.

Both began the counseling assuming that all needs would be met by the well spouse but quickly saw that this was unfair and together sought areas where care could be delegated.

A result, Dr. Whitlock said, was that patients felt involved in the decision making and caregivers felt relieved at having more options than they had imagined, sometimes even the acknowledgment of the ill spouse that a nursing home might someday be necessary.

The groundwork for the current self-help movement is the 20-year-old work of Robyn Yale, a social worker in Northern California, who ran patient support groups when most Alzheimer's agencies considered them incapable of benefiting. Ms. Yale is now organizing groups for early stage patients in assisted-living centers and nursing homes.

"It's been a long process of changing stereotypes," Ms. Yale said. "But we're finally hearing their voices, and we need to respond to that."

One frustration among innovators in the field is creating volunteer opportunities for people who are too forgetful or confused to do many jobs. An agency tried that in California, pairing a cognitively intact volunteer with a second volunteer with mild dementia, but, over time, the labor-intensive project could not be sustained.

Last year, the national office of the Alzheimer's Association declared early stage services a priority. The association now has an advisory board made up of patients, most whom have a rare early onset form of the disease, which sometimes runs in families.

People struck with dementia of various sorts in the prime of life — 200,000 to 500,000, according to last week's study — have been the most aggressive advocates, experts say. They have not settled into retirement or been slowed by other infirmities, and they also came of age in an era of activism.

"This younger group, we're mouthy," said Chuck Jackson, 53, one of the board members, a former outplacement counselor for loggers who left his job upon diagnosis, wanting to "enjoy daily life" as long as possible.

"I know where I'm going to end up," Mr. Jackson said.

So do John Carpenter and Mary Carver, but they are not there yet.

Mr. Carpenter, who once performed in Broadway musicals, was determined to perform again after his illness was diagnosed recently at age 82. One of his "big hurts," Mr. Carpenter said, "is not knowing what I'm going to do tomorrow or the next day or the day after that." His wife, Milly, "doesn't talk to me like she used to," he said.

"And," he added, "when people say, 'Tell me what you did,' it's gone, just gone. I want to be who I was."

So he petitioned the Alzheimer's Association to let him star in a play about the disease. And he and Ms. Carver, a former singer, told Ms. Michaud, the group leader, that they would enjoy performing together. Could she help them find an adult day care center where they could entertain? She can, and she will.

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