



Living Fully With Alzheimer's

10 strategies for keeping loved ones connected to family and community.

by: Sarah Mahoney | from: [AARP](#) | November 3, 2010

In warm weather, 81-year-old Libby Nye spends time with friends and family in New Hampshire, soaking up sun at the lake club. And during the winter months in Florida, she and husband Joe golf. While the adjustments they make to accommodate advancing [Alzheimer's disease](#) seem relatively small — "scoring is too confusing, so I'll play a few holes now and she putts," Joe says — the Nyes are on the edge of a revolution in how America handles [dementia](#).

"I'm sometimes embarrassed," admits daughter Susan, 55, who lives in New London, N.H. "Mom may interject nonsense into a conversation, like blurting out 'Eenie, meenie, miney, mo.' But the people who know and love her can understand what Alzheimer's is doing to her, and make adjustments. And if they can't, they were never really our friends in the first place."

William and Joan Speidel, 75, of Macon, Ga., would agree. Since Joan's diagnosis last year, they make regular appearances for the local [Alzheimer's Association](#). "Joan is very open," William says. "She may be losing her brain function, but she's not losing her heart. We're making an impression about what Alzheimer's can look like, and that makes us both feel good."

These families are part of a blossoming civil rights movement. "We've got an advisory board of members in the early stages of the disease who constantly remind us: 'We are out there, and people are going to see us out there.' The more patients and families speak up in public, the quicker the perception of Alzheimer's will change," says Beth Kallmyer, a social worker with the national Alzheimer's Association in Chicago.

It's a movement fueled by astounding numbers: About 5.3 million Americans have Alzheimer's; worldwide, 26.6 million have it (by 2050, experts expect the population will soar to 106 million). [One in five women](#) will develop the disease, and one in 10 men; it is more common among African Americans and [Latinos](#). On average, people live between eight to 10 years after they are diagnosed, and 70 percent receive care at home. Given those realities, working harder to include Alzheimer's patients in more aspects of daily life is not only the best option — it is the only practical option for their families.

But that's not to say it's always easy. Because Alzheimer's has so many disconcerting [symptoms](#) — patients may blurt out swear words, start undressing at the dinner table or become very fearful — families often begin to become more isolated, bringing their loved ones out as little as possible. Sometimes that isolation makes sense. "As you get into the later stages,



Ocean/Corbis

"People who know and love her can understand what Alzheimer's is doing to her, and make adjustments. And if they can't, they were never really our friends in the first place."
— Susan

Share Your Photos

What Alzheimer's "looks like" varies as much as the people it affects. [Submit present and past photos of your loved ones](#)

it's not always great to change environments," says Dr. Ken Robbins, a clinical professor of psychiatry at the University of Wisconsin-Madison, who helped develop the "Steps & Stages" forums at Caring.com, which offer [stage-specific support for caregivers](#). "Even a trip to a restaurant can be disorienting." But often, experts say, it's a self-imposed exile, part of the distress over the way Alzheimer's eventually steals the people we love.

for possible inclusion in an AARP.org Alzheimer's tribute. **Do**

Still, there are plenty of ways to keep Alzheimer's patients connected, strengthening their ties both to the outside world and their families:

Take it day by day. When families are first taking in the diagnosis, "it's hard not to fast-forward to the worst possible scenarios, a tendency experts call 'catastrophizing,'" Kallmyer says. "But it's important to remember that every case is different, and develops over time. As more people get diagnosed early, still living their lives, Alzheimer's turns out to be not as paralyzing as many families imagined it might be."

Keep routines going as long as possible. Linda Leonard, 59, of Arnold, Md., loves bringing her mother to weekly religious services. "Even though she is confused, this place is familiar to her, and these people have known us a long time," she says. "They know she's ill — they don't treat her any differently." For Luckie Daniels, 44, and her

mom, Geraldine, 69, both of Atlanta, the meaningful ritual is their regular Saturday trip to the bookstore. "She and my 3-year-old daughter will sit and look at the children's books, and I feel like it's one small way we can hang on to a normal weekend."

Time is short. Stop arguing. Many family members constantly correct the patient, whether it's during the relatively minor stages of confusion, or later, "when many people develop delusions," Robbins says. But setting them straight is pointless. "First, they won't remember it. Second, it puts you in an adversarial role, and that takes away from your ability to enjoy spending time with each other." Nye has learned not to respond, for example, when Libby pleads with him to take her home. "For a long time, I would say, 'You are home — I'm your husband, these are your clothes.' Now I change the subject, and say, 'Let's go [for] a walk.'"

"But honestly, people with Alzheimer's have the right to go shopping, too — I was livid." — Luckie Daniels

Find their greatest hits. Dig into your loved one's personal musical history and find out what songs were big hits in the patient's late teens and early 20s, suggests Sharon Gregoire, 59, an occupational therapist and author of a workbook called *I Still Enjoy a Good Laugh - A Guide for the Journey Through Alzheimer's Disease*. "While they'll respond to any familiar music, the music they first danced and fell in love with, like the jitterbug, will really open them up." (Not sure which songs might suit? Just typing "greatest hits 1939" into iTunes will lead you straight to Judy Garland's "Over the Rainbow," Billie Holiday and Glenn Miller, for example.)

Talk less, do more. As the ability to chat fades, it can be tough for family members to feel connected—visits can start to feel strained. "Find small jobs they can do, like shucking corn, folding towels, or winding a ball of yarn," Gregoire says. Also, when her father, a retired farmer, was too ill to walk around the fields, she would bring him gifts such as a handful of fresh-cut hay to smell and touch. "Even a box of bolts to unscrew can make the difference between an hour of frustrating conversation, or one when you get to pass the time together pleasantly."

Counter intolerance. When Daniels took her mother dress

Chat About Alzheimer's Disease and Caregiving

[Sign up for a live online chat](#) with AARP caregiving expert Elinor Ginzler and family expert Amy Goyer on **Friday, Nov. 5, from 1 to 2 p.m.**

shopping for Thanksgiving last year, "a woman standing behind us was talking on her cell phone, complaining about how slowly we were moving. I couldn't help myself — I turned around and told her mom has dementia and it takes her a little more time to make up her mind. The woman was mortified--and her husband was so embarrassed. But honestly, people with Alzheimer's have the right to go shopping, too — I was livid." Kallmyer says some people even like to carry business cards with messages like, "Thanks for being patient with my husband — he has Alzheimer's," as a way to let waitresses, tellers and sales clerks understand that they may need to take a little extra time.

Related

(EDT). [Do](#)

- [Experimental Therapies for Alzheimer's Patients. Read](#)
- [When a Spouse has Alzheimer's. Watch](#)
- [Alzheimer's Photography Project. Watch](#)
- [Maria Shriver on Alzheimer's. Listen](#)
- [Can You Walk Away from Dementia? Read](#)

Don't confuse the disease with the person. It can be disturbing to watch a once polite, understanding person morph into someone who can't sit still, spits or even bites. "It's important to remember this is not the true person," Robbins says. "Sometimes people think they always had this repressed meanness inside, and that Alzheimer's just liberates it. But that's not the case. The disease has damaged their brain—this isn't the true them."

It also helps, Kallmyer says, to know that keeping patients involved and engaged in any way helps them. "Eventually, the public will understand that people with Alzheimer's need to have meaningful engagement with people every single day," she says.

Reinvent family get-togethers. Surrounding Alzheimer's patients with their families is good for everyone — it can help the patient's memory and mood, and help family members feel involved. Leonard, for example, enjoys her family's traditional Sunday dinner, which gives her siblings a chance to spend time with both parents. Sometimes, though, crowds can be overwhelming. Gregoire, who is one of 10 children, says it helped to actually assign someone to her dad for each hour. "We'd create a calm corner where he was comfortable, and take turns watching him. If he needed a break, that person would take him outside or to another room."

Feed your own passions. [Caregivers need more than a little relief](#) now and then: They need to have their own hobbies and outlets, something Debbie Mandel author of *Addicted to Stress*, calls "creative compensation." For Speidel, it's bowling or a day in the woods hunting birds. For Nye, it's golf three times a week, no matter what. "This disease creates a void," says Mandel, who had two parents with the illness. "We need to help fill it with something good."

Surrounding Alzheimer's patients with their families is good for everyone — it can help the patient's memory and mood, and help family members feel involved.

Keep your heart open for magical moments. "I peeked out over the banister recently and my mom was sitting in the living room, listening to my son and daughter play their guitars. She was saying, 'You're such a good big brother. Will you promise to take care of your sister, even when I'm not around?' I just wanted to melt," says Daniels.

And on a cruise to the Arctic Circle, Speidel surprised Joan with a ceremony to renew their vows, a day filled with orchids, champagne and chocolate. "About 50 people we met on board showed up, and they were so kind," he says. "It's amazing how caring people can be if you just talk to them about Alzheimer's."