

# A Family Holds On

***When Alzheimer's strikes early, life turns upside-down as children and spouse begin a slow farewell.***

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Al Rhodes-Wickett hadn't been acting like himself for quite a while, and his family was worried. When the doctor called one afternoon, his wife, Sharon, disappeared into the privacy of a back bedroom. Their teenage children, Rachel and Ben, feared the worst: Cancer? A brain tumor?

The diagnosis: Alzheimer's disease.

***The kids were stunned. How could their father, a musician and Methodist pastor, have Alzheimer's? He was only 55.***

Rachel, then 18, looked up Alzheimer's in a medical encyclopedia that evening in March 2001. What she read didn't fit her dad. It said the memory-robbing disease occurred in those older than 65 and was "invariably fatal." Her mind jumped ahead—to her wedding day, to having children, to all the pivotal moments she and her 14-year-old brother might not be able to share with their laid-back dad.

The experience of the Rhodes-Wickett family is at odds with our image of Alzheimer's disease. We tend to envision Alzheimer's

patients in their sunset years like President Reagan or the frail elderly who populate nursing homes. We don't picture physically robust men or women whose sons and daughters have geometry homework and soccer practice.

As the baby boom population grows older, there will be many more families like the Rhodes-Wicketts. Sharon, 53, and Al, now 56, like many in their generation, delayed childbearing until their 30s and 40s to pursue careers. They were blind-sided by an Alzheimer's diagnosis with the kids still at home, college ahead and Medicare help years off. Their story and that of families like them has been little told.

***400,000 people diagnosed each year with Alzheimer's are younger than 65***

Although no one tracks early-onset cases, the Alzheimer's Assn. estimates that as many as 10% of Alzheimer's patients or 400,000 of the 4 million people diagnosed each year are younger than 65. An unknown percentage of that group is still caring for children. If current trends continue, more than 513,000 American men and women between 45 and 64 might be affected by the beginning of the next decade, estimates Shin-Yi Wu, a health researcher with Rand Corp., a Santa Monica think tank.

"We're going to see more and

more of this," says Harvard University neuropsychologist Marilyn Albert, noting that improved diagnostic technology is helping doctors make earlier and more accurate diagnoses of Alzheimer's.

The disease profoundly alters family dynamics. The healthy parent often becomes primary breadwinner, arbiter of family disagreements and principal caregiver. As the affected parent is less able to function independently, the spouse and children step in with reminders about medicines, social cues and assistance with irretrievable words.

## ***Kids Face Role Reversal***

All this can turn life upside-down for children used to depending on that adult for security and stability. A parent who once made them feel safe suddenly needs their help. The role reversal forces them to grow up fast.

There's no blueprint for dealing with an Alzheimer's-stricken parent. No handbooks. No Web sites. No chat rooms. The few materials from the Alzheimer's Assn. speak mostly about when Grandma or Grandpa, not Mom or Dad, develops the incurable degenerative illness.

"I can't give the kids a book because there's nothing written from their perspective, based on their needs," says Laura Rice-Oeschger, a social worker in Northridge for the Alzheimer's Assn. of Los Angeles. She just organized a retreat for the half-

dozen teenage children of her early-onset support group.

For many of them, home may no longer feel like a haven. With Dad or Mom no longer his or her old self, it can be tough to explain the nature of the illness to peers who want to know if the affected parent is getting any better. Often kids become reluctant to burden the rest of the family with their problems or emotions--at the time of their lives when they most need help.

That's been the case for Al and Sharon's younger child, Ben, 16.

"We already have a whole lot of problems, and I don't want to add to it," says Ben, who became so depressed and distracted by his dad's illness that he flunked a history class. Therapy and antidepressants got him back on track. Music helped too.

A bassist whose band, Kill the Sound, recently performed at the Whisky on Sunset Boulevard, he says getting out means "I don't think about anything at home. I can actually have fun." He dreams of a college where he can snowboard, maybe in Oregon.

But he'll probably have to start at a more affordable community college. Alzheimer's care drains family savings.

Rachel has spent two years at Santa Monica College but has hopes of transferring elsewhere. She's been able to save money on housing and tuition while being near her dad: "I felt if these are his good years, and these are his lucid years, I don't want to miss them."

As Alzheimer's ravages the brain, it can make a parent behave in ways that seem out of character. Rachel has learned to blame the

condition, not her dad, for the important things he has forgotten to do and say and for an aloofness that sometimes made her think he loved her brother more.

"Once you find out it's Alzheimer's, you can trace it back and look at all the things you blamed him for in the past," says Rachel. "There's a lot of forgiveness that can happen."

There have been other gifts too: She and Ben have drawn closer. Rachel calls her brother "the only other person on Earth that's really going through the same thing."

Yet even though they may seem to be coping, sons and daughters of early-onset Alzheimer's patients inevitably worry about their own neurological health. Unlike late-onset Alzheimer's, which has multiple causes, most early-onset stems from gene mutations passed on by one parent. In families with these mutations on chromosomes 1, 14 and 21, the kids have a 50-50 chance of developing the disease relatively early in life.

When doctors first told Al that the Alzheimer's probably came from his father, he thought: "If my dad gave this to me, I don't want to be giving it to my children." Says Rachel: "I'm OK about getting Alzheimer's at 85, but not at 45."

Ben says he tries to reassure himself that by the time he might get it, there will be a cure.

### ***Planning for the Future***

Alzheimer's can dash even the best-laid plans.

Al and Sharon, who met while studying for the ministry, always found a way to accommodate each other's ambitions. When Sharon worked nearly round-the-clock as a district superintendent for the

United Methodist Church, Al did the lion's share of parenting, shopping and housekeeping. When Al took sabbaticals from his congregations to work on his music, Sharon shouldered the financial burdens. Now she has no choice but to carry the load alone.

Since Al left his church in Torrance and began collecting disability benefits in January, Sharon has tried to square away the family's modest finances and put something aside for the kids. She paid off one car and put some money into IRAs. Because Al's driver's license was taken away last month, she will put his car in Rachel's name.

Sharon, the pastor of Westwood United Methodist Church, shared Al's diagnosis and her feelings about it in a letter to her congregation just after Easter last year, telling them: "You will find that sometimes I can talk about it quite rationally and calmly; then there are times when the tears are just ready to spill over."

Alzheimer's is hard not only on the patient's children, but on the spouse or partner as well. The disease can cause the affected person to become withdrawn, creating feelings of loneliness and frustration in the other person at a time when he or she most needs support.

The loss can seem doubly cruel to a couple who had expected many more years together.

Although Sharon had a phase of being "obsessively scared about the future," she now feels "that one way or the other, I'll be provided for, my kids will be provided for and somehow we will manage."

But the plans she and Al once had to buy a little piece of property for their retirement years, for example have evaporated.

The future, Sharon says, "now looks more like a solitary prospect for me."

She'll work as long as she can, which brings not only income but health insurance for Al. But even that benefit has its limits. Al had to enroll in a UCLA clinical trial to get Reminyl, one of the three medications that helps Alzheimer's patients function better even as their brain cells are dying.

All things considered, Al is doing well, according to his UCLA neurologist, Dr. Verna Porter.

He still has some insight into his illness, and says that without the identity and income that work gave him, he feels "as if a large part of me is just floating someplace."

He wonders what contribution he can still make.

He's trying to finish his fourth musical before the forgetting takes over.

At some point, Porter says, he won't recognize his wife or children. "When it's a loss of connection to their lives on a daily basis, that's going to be a turning point."

Alzheimer's brings about mental followed by physical declines, but doctors don't agree whether early-onset patients decline at the same rate as the majority of patients.

Some say the end will come more quickly; others say their relative physical health will keep them alive longer, even after their mental faculties deteriorate.

Regardless, all patients eventually need full-time care. Sharon is thinking about a retirement community for religious workers that offers assisted living and nursing services.

### *Focusing on the Present*

Twenty-two miles from the Rhodes-Wickett house is the San Fernando Valley home of Dave and Shelly Rothberg. The couples attend the same Alzheimer's support group.

Dave, now 63, was diagnosed with Alzheimer's two summers ago, just before his daughter Sarah's bat mitzvah, making bittersweet the ceremony marking a Jewish girl's passage into adulthood. He retired from his law practice a couple of months later.

The Rothberg family defuses frustration with laughter and easy banter that can make it look as though nothing's wrong. For a long time, Dave and Shelly, 52, refused to believe that Dave's memory problems were serious. But like many perceptive kids, Joseph, 16, began putting the pieces together.

He suspected something was wrong six years ago when he beat his father at chess for the first time; Dave's victory had always been a foregone conclusion. A few years later, when Joseph's Hebrew school class watched a video about Alzheimer's, he read the list of warning signs and gasped: "Oh my God, my dad has every single one of these." He didn't breathe a word to his mother because he didn't want to worry her, a protective instinct he shares with other kids.

Driving is a milestone for any teen, but even more important for

Joseph. The day he got his permit, his father got a DMV-issued California ID card to replace his relinquished license. Joseph's role as No. 2 driver has been hard on his sister, Sarah, 14: "Joe can do something for the family that's productive, and I really can't." She's also lost that quiet time in the car with her father: "My dad and I used to bond when he drove me places." Like many Alzheimer's families, the Rothbergs know tomorrow rarely brings good news, so they're taking vacations together now, while Dave still enjoys traveling.

For spouses and children, the hardest thing may be watching the person they know disappear a little bit more every day. But experts and families say that what's important is to focus on the present-- not on what has been lost, but on what's still there.

"Remember the person he or she was and still is on the inside," says Rachel Rhodes-Wickett. Looking ahead to the inevitable, she says that what she wants from her father "is something he's already given me. He's a great father. That comes from being a good human being. He couldn't give me more of that if he lived 100 years."

Resources for Alzheimer's Disease or information on Long-Term Care, Annuities and Life Settlements is available from Gary Crystal at the Crystal Insurance Group (818)992-5678 (877)822-5678.

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