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Alzheimer's hits family hard: 'Something's not right with Mom . . . and now, Dad.'

Watching one parent die by inches is painful enough. When Alzheimer's takes both, your pain is more than the sum of the parts.

By Melissa Isaacson

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It is a simple television remote. But it is making our family crazy.

Cable TV has arrived at my parents' house, and with it has come a more complicated channel selector, which I have painted with red nail polish to designate the key buttons for them to push. But this is obviously not working.

Nightly, we wait for the phone call.

On this particular evening, my mother is hollering at my father, I am shouting at them to call my brother Barry for help, and my husband is imploring me to stop yelling.

I do not realize I am yelling. I do know I am shaking.

"Dad," says Barry, when his phone rings, "do you see the number 5 on the clicker? OK, good. Now do you see the word 'Enter?' OK, push the number 5 and then press 'Enter.' "

Barry hears a beep in his ear as my father pushes the number 5 on the phone. My brother then gets in his car, drives the 15 minutes to our parents' house and changes the channel.

Clearly, things are getting worse.

It is 1993. Our mother, Francine Isaacson, is 66; our father, Herb, is 72. And we are losing them. Physically, they look terrific. Mentally, they have been on a slow, steady decline. We don't use the word Alzheimer's yet.

My parents are not exactly Ward and June Cleaver, but not in any bad way. Unlike June, my mom doesn't wear dresses and pearls when she cooks and she is not cheery at breakfast time. Unlike Ward, my dad enjoys the occasional scotch after work. They also have four kids, not two, and none of us makes it through a day without multiple kisses, hugs and "I love you's," just in case one of us decides to ship off to the Peace Corps upon leaving the house.

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My mother has shrugged off severe physical discomfort for most of her life. It has been her habit to walk like a fiend, sew, cook, bake, garden, needlepoint, knit, decoupage pictures from art books, refinish furniture, read two newspapers a day, half a dozen magazines a week and, when the pain from a long ago injury keeps her up at night as it so often does, polish off another novel.

She also has been one to get her hair wet swimming, shoot baskets in the backyard and follow the Bears as if they were her own sons.

My father is in the scrap-iron business, a 9-to-5, suit-and-tie man, despite the fact that he often spends his days in filthy scrap yards and occasionally takes the wheel of one of his trucks. He is

razor-sharp with numbers, conservative with a buck and trades his tie for a sweatshirt after work to coach my brother's Little League teams--this despite the fact that most games of catch end with him breaking his glasses.

My mother makes a living laughing at my father, who is among the most gullible men on Earth. He always gets the joke eventually, it's just 20 minutes or so after the punch line. We call this, and the fact that he can never find his glasses, absent-mindedness. And when my mom misplaces her purse and refers to us by each other's names, we call it having four kids. Their doctor tells us years later that he has never seen a couple at their age become mentally impaired at the same time and deteriorate at such a similar rate.

Because of that, "They couldn't help each other," he told me.

In many ways, my family's story is universal: We grow up. We lose our parents. This, my mother always said, is the natural order of things. She did not talk much about what came in between.

Caring for elderly parents, watching them decline, worrying about our own genetic fate--it is a part of life for many Americans past the age of 40. I first began thinking about it as a little girl. By my mid-20s, I was living it. And by 40, I was still no better at it.

There are no guideposts for Alzheimer's, which afflicts more than 5 million people in the U.S. and is a "virtual epidemic" as Baby Boomers age, according to Dr. David Bennett, the director of the Rush Alzheimer's Disease Center. As our own parents retreated further into the depths of the disease, the more clueless we all became.

"Something's not right with Mom," I had told my brother Richard in 1991.

Richard was trying to tell me about our father, who was insisting that something was wrong with his eyes--in Dad's mind, perhaps a complication from cataract surgery.

He was tripping often, grabbing at things that weren't there and missing by miles things that were. But then, just as oddly, he could read a sign from so far down the street that we could barely see it. And every time my brothers took him to eye doctors, they would pronounce him fine.

My mother, meanwhile, was slipping downhill right under our radar.

"What's wrong with Mom?" my brother asked with some surprise.

I told him about the 5-minute phone conversation she and I had had the day before. A half-minute later, she had called back. Same greeting, same news, same exact conversation until I blurted out, "Mom, you just called and told me that a minute ago."

"What are you talking about?" she said angrily.

"You just called me," I told her. "You just told me that."

"No, I didn't," she said.

Our conversation was over, but I stood holding the phone for a very long time.

Several appointments were made and then canceled at Rush Medical Center's Alzheimer's Clinic over the course of 1991 and '92. My mother refused to go, even though we went out of our way not to use the word Alzheimer's, a tactic undermined when we finally got her there and Barry and I estimated the word "Alzheimer's" on the wall to be approximately 12 stories high.

I sat with her while she was given a blank clock face and was asked to draw the hands at 3 o'clock. I stared in amazement as she drew three squiggly lines pointing to 12. How did I not realize she was this bad?

Several times in the weeks and months that followed, when I thought my father was not exercising enough patience with my mother, I told him, "Dad, Mom has Alzheimer's. Do you understand that?"

But of course he didn't, because he had it too.

At my wedding the previous fall, both had looked healthy on the outside, yet my father could not grasp how to walk down the aisle or where to stand once he got there.

During one of my mother's appointments, Barry convinced Dad to be examined, and eventually it was explained to us that Alzheimer's manifests itself in different ways. Whereas my mother's symptoms were the classic ones--a fairly dramatic loss of short-term memory--my father's were, at first, more physical. You handed him a glass and he reached for his knee. You told him to touch his knee and he touched the couch.

Through all of this, my mother continued trying to maintain the sense that everything was fine. A few times a week, I would bring over dinner. "Just put it in the oven for an hour at 350," I'd say, and she would nod. I'd repeat it a few times for good measure and then leave, telling myself they were all right. It wasn't until years later that I seriously questioned whether they had been eating much at all during that time or maybe just spooning out cold spaghetti, a thought I cannot bear.

Eventually it would become clear that they need help in the house. They are, of course, against it.

"They [caregivers] wouldn't have to live there," my brothers and sister say. "They can come and help with meals and then leave after dinner."

My mom is afraid of surrendering her home to strangers. My dad is afraid it will cost too much and that the caregivers will steal their money. He is right. One caregiver, we later learn, tried to put him on the phone to authorize an ATM code so she could get a card and withdraw cash.

My mom is right too. An immaculate housekeeper, even her junk drawer is a thing of beauty, and her kitchen smells are always delicious and welcoming. But we can't preserve that. We can't even try. The caregivers are there to take care of our parents, not to be personal chefs or cleaning ladies. That said, it is still terrible to walk into the kitchen and smell something strange and unpleasant or worse, smell nothing at all.

The years following my parents' "diagnosis" (there is no fully reliable diagnosis for Alzheimer's while the patient is still living) tend to blur together. What I remember is my mother growing more

and more anxious whenever she left her house, asking the same question three and four times in a row, drifting ever so slowly away from us.

But then are the moments that are seared into my brain, like the sound of my baby bouncing down the stairs.

It is 1996 and Amanda, our daughter, is in that deceptively fast crawling stage, 9 or 10 months old, that allows her to climb up two steps and fall down six in no time. But she is still in that soft, mushy state that protects her as she slides down.

I hear the bumpety-bump-bump-bump first. Then the eerie pause. Then the cry. My husband, Rick, and I quickly arrive and scoop her up, both registering the same thoughts: Thank God Amanda seems fine, and who is to blame for taking their eyes off this child?

It is our fault. Amanda had been in the living room of my parents' house and I thought Rick was watching her play with my mom, while he thought I was. It has not yet hit us how important it is that someone besides my mom be there.

"Mom, weren't you watching her?" I say angrily as the baby continues to scream in my arms. "She fell down the stairs."

And then my mother--my funny, brilliant, loving mother--looks up and says something I will never forget.

"Why is that baby crying?" she demands. "Who is that baby crying?"

I remember a day in the early 1970s. I am 8 years old and, as usual, I am glued to my mother's side.

She is holding my hand as we walk. My mother never learned to drive after her accident when she was 19. She had been visiting her sister Pearl's family in San Jose, Calif., and was on a double-date with a girlfriend and some naval officers, picnicking and hiking, when she tripped and fell off a bluff. She rolled for nearly 80 feet, then fell straight down, ending up in a dry stream bed more than 100 feet below, her petite body battered with internal injuries, a pelvic fracture, a lacerated eye, a shattered elbow.

It was that right arm, held together by what would be a series of prosthetic elbow replacements, that would be the one lingering injury, a disability that in many ways defined her, but rarely stopped her, except when it came to driving. Legend had it that my father once tried to teach her, but that experiment quickly ended when they jumped a curb on McCormick Boulevard and came very close, in my father's mind anyway, to a canal.

And so here we are on foot, crossing Devon Avenue, when we spot an elderly woman in a woolen sweater. It is maybe 80 degrees out.

"You've got to promise me," my mother tells me, and I know where we are going with this.

"I know, no sweaters in the summer," I say, giggling.

"I'm serious," she says. "They'll put me in sweaters and you know how I hate being hot."

"But maybe you'll be cold."

"I won't be cold."

"OK, Mom. No sweaters."

I am a kid, but I get it. It is the running joke in our family. Susie is the oldest of my siblings, 12 years my senior, then Barry, nine years older, then Richard, seven. And one thing is clear to me.

"We have Missy to take care of us in our old age," my father says to people with a wink.

I have no problem with this.

"Will I still be your baby when you're 70 and I'm 30?" I say to my dad, as preposterous as it sounds that I will one day be 30, much less that he will be 70.

"How about when I'm 40 and you're 80?" I say, and again and again until I am 110 and he is 150.

"I'll be in the old people's home by then," my dad says, to which I always reply, "Oh no, Daddy, you're always going to live with me."

Shortly after our family's Alzheimer's journey began, a friend whose father had the disease gives me this advice: "Cherish each day," she says, "because it just keeps getting worse."

Great, I think. I'm supposed to cherish the first time my mother forgets my birthday? The day I tell my father that my husband and I are expecting our second child and he reacts to the news as if I'm 15 and telling him my boyfriend got me pregnant?

One of the early stages of Alzheimer's can be combativeness and denial. Often, the afflicted person tries to cover up the memory lapses. I know my mother is doing this. But I am convinced that she could preserve her faculties if only she would try harder, keep lists, write everything down. I actually suggest this.

Barry doesn't. When my father insists he wants to go home when he is already there, or talk to a friend who died years before, or be taken to his office at 10 at night, my brother puts him in the car and drives him around the block until Dad is satisfied that he is at his destination. Then Barry takes him in the house and puts him to bed.

He reasons that it is easier to do this than to argue. But we know he does it in much the same way you give medication to someone in pain. He does it to give our father comfort in the only way he can.

My father's checkbook is a major point of contention. It is a business checkbook, a large black vinyl spiral that, as a child, I always thought looked very important, and I associated it with him as much as his watch or his glasses. It is hard to tell what his association with it is anymore, but he is obsessed with it. He needs to know where it is at all times and he needs it to stay under his control. And that is it, obviously. It is pretty much the last vestige of control for him, long after he is able to write checks or even know what one is. If Barry dares take it home for even one night to pay bills, my dad invariably notices and demands that he drive it back. Barry does, of course, and begins doing all the bookkeeping at their dining room table.

For my mother, the big issue is her engagement ring, her most treasured possession. She has never worn much jewelry, but she rarely removes her ring, a beautiful marquis-cut diamond that my Uncle Norvell, a jeweler, took great care in selecting for my father. I would stare at it when I was little, dreaming of the day I would have one, but there was no dancing around the house with it, pretending it was mine. If she took it off to stick her hands into dough or meatloaf, it did not leave her sight and was put right back on afterward.

In recent years, though, she has gotten into the habit of giving or throwing away valuables. It scares us that the ring will be lost or stolen. But the mere suggestion that we keep it safe for her makes her nervous and angry, so we have stopped bringing it up.

I have never spoken to Barry about the day he took Dad's checkbook for good. But I know how I feel when their caretaker, Maria, hands me my mom's ring and tells me I need to take it home with me.

I walk out feeling as if I am stealing a part of her.

For years now, Maria and her husband, Jimmy, the latest caretakers and by far the best, dress our parents each day, put makeup on my mom, fix her hair and try to simulate some sense of a relationship between two people who have lived together for more than 50 years and now barely know the other is there.

Occasionally, they speak to one another, though very rarely in any manner that makes sense. But every night, after dinner, Jimmy and Maria sit the two of them next to each other on the den couch, place my mother's hand in my father's and leave them there alone together. They never pull apart, Maria says. Somehow, this is one thing that seems to make sense to them.

In stages, we have mourned the loss of each attribute that has made my parents who they are. But it is happening so much faster now. Our mother, with her edgy humor and sarcasm, has become docile, almost childlike. Her moments of clarity--minutes, sometimes seconds when she would seem to realize what is happening to her and begin to cry--no longer occur.

Our father has gone from shuffling to not walking at all; from us wondering how bad his eyesight is to the certainty that he can no longer see.

There is a fall that causes a hip fracture, and with subsequent hospital stays for relatively minor ailments, he sinks further away from us. It is, a doctor explains, as if he is on a fence, each small trauma pushing him further onto the side of dementia, never to completely return.

Then one day his doctor refers to him almost casually as "end-stage." Not long after, we decide to let our father starve to death.

This sounds awful, I know. But if I kept a journal, that would have been my entry for Jan. 20, 2004, the day my father officially stopped chewing, swallowing or accepting food or drink.

Alzheimer's patients, we learn, often die this way. They eventually simply forget how to swallow. But it is one thing to know this and one thing to really understand when the time comes.

A feeding tube is some people's answer, but it would require a surgical procedure with some risk of infection. Besides, some day we might have to decide to remove the tube, and then we would be playing God.

But to let him starve? It seems barbaric until one of the hospice workers hands me a pamphlet that explains issues the doctor did not. Death to those who stop eating in end-stage Alzheimer's does not come because of starvation, it explains, but rather dehydration, a peaceful, humane way to go. Several doctors I consult tell me the same thing, as does our rabbi.

There is no indication Dad is in pain, only that he is growing weaker. Hospice is there to monitor, to check his vitals, to administer medication if they think he needs it, but for the first time in a very long time, our father is in control.

My father spends his last hours in a hospital bed in my brothers' old bedroom off the den. There,

where my mom sewed the curtains and bedspreads and my dad yelled at my brothers to cut out the monkey business, everything has been cleared out but the bed and the medical supplies.

I wouldn't say watching someone you love die, even at an advanced age, is something I would recommend, and I would not use the word "peaceful" to describe it. But we are there, taking turns holding his hand, waiting for his final breath, which Maria, who had been a nurse in the Philippines, says is coming soon.

His breathing is so shallow and irregular, I wonder if we'll know. But you know. There is a slight grimace and then one solitary teardrop rolls down his cheek.

I used to say his existence over the last few years was no life at all. But I am wrong. This is no life at all. And the finality weakens me. We walk out of the room and look at my mother, sitting in her chair, staring ahead. We give her hugs and kisses and with an old familiar grin, she looks up at us. We do not say a word. And for the first time ever, I am glad she has Alzheimer's.

About a year later, I am in California to interview Michael Jordan for a story on his new career in motorcycle racing. But it has been put off for a day, which leaves me with little else to do but sit in the hotel and watch the endless cable news loops. On this day, they focus on the death watch for Pope John Paul II and the ongoing case of Terry Schiavo, the 41-year-old woman who has been in a persistent vegetative state for 15 years and whose husband wants to remove her feeding tube.

I doze off as they interview someone saying that such a way of dying is akin to torture.

In the dream, I am sitting on a big fluffy bed with my mom, who for the first time in years talks to me with clear eyes and a strong voice. God, how I miss her. "I think I'm going to go see Dad," she says matter-of-factly.

It does not seem like she is talking about going to the Great Beyond. But clearly she thinks she should be with my father, wherever he is, and just as clearly, I do not want her to go.

"Really?" I say. "But I want you to stay. I'd miss you too much if you left."

I hold her tight and tell her again that I don't want her to go. "OK," she says. "I promise, I'll stay here with you."

I wake up in my hotel bed with the warmest, most contented feeling I can imagine. For about five seconds.

And then I cry.

My mother and I have always been exceptionally close. She has always known what I was thinking and how I was feeling with spooky accuracy and I often felt equally attuned to her. But over the last few years, I have lost it. I would give anything to know what she is thinking and how she is feeling now. But like my father, her eyes have permanently shifted away from whatever is in front of her to a blank stare that focuses on nothing. And I strain to remember the sound of her voice, as she has stopped talking altogether.

If she has a subconscious that is still working, I just can't pick up the frequency.

But that was her in that dream. She was there, talking to me, telling me she wanted to go. And I wouldn't let her.

Fourteen months earlier, shortly after my father stopped eating, when it was clear his body wanted

to give up but his will would not allow it, the social worker from Hospice took me aside.

"You need to give him permission to die," she told me.

"What?" I stammered.

"Your father is hanging on, and sometimes they just need to be told it's OK to go. Even if it's not in his head, but in his soul," the social worker said, "he will hear you."

This actually made sense. A few days before, weeks since he had last spoken and semi-conscious at best, he had called out my mother's name.

"Honey?" he said loudly. "Where's Francine?"

It wasn't going to be easy for him to leave her.

And so I told my father that it was OK to die. I know I rambled and repeated myself. But as I sat on the arm of his recliner, my head against his, he actually turned his cheek toward mine and somehow I knew he heard me.

"I'm going to miss you, Daddy," I whispered. "I'm going to miss someone worrying about me the way you always have and loving me the way only you could. We love you and it's OK. You did your job. You did a fantastic job. You can rest now. I promise we will take care of Mom for you."

He never was a great listener, my father. He hung on for six more days.

Now, a year later, what little quality of life has remained for my mother is dissipating. But I can barely bring myself to speak out loud to her any more, much less tell her it is OK to die. It is not OK, much as I tell myself that's selfish.

And now she was coming to me in my subconscious, telling me she wanted to go and all I can do is beg her to stay.

How am I going to make that OK?

The nursing home where we move Mom is one of the better ones. At least that's what we tell ourselves as we bury our father, pack up our parents' belongings and sell the house where they have lived for the last 49 years.

I think about my mother saying this was the natural order of things, but no one can ever tell me that it's natural to put a parent in a nursing home.

The truth is, she would have understood that too. In all the kidding about not putting sweaters on was the explicit understanding that we would be the ones to make the final decisions and that was fine by her. In fact, the less she knew, the better.

And we are all reasonably sure as we move her to her new home in the spring of 2004 that she has little, if any, idea that she is leaving behind pretty much every semblance of life as she knew it.

We try to make the room homey, decorate it with old photos, a painting, mementos she cannot process. When people ask if she recognizes us, I shrug.

There is no reason to think she knows who we are. Her expressions, if any, do not match the occasion. Her voice has been silent for more than two years. And yet, when we hold hands and she

rubs her thumb across my fingers as she always has, I tell myself she knows it is me, even when I see her do the same thing with a nurse or social worker.

Over the next three years, the nurses tell us they love her, which I like to hear but wonder why. I have tried to tell them of her "real" personality, of her kindness and sense of humor, but they receive absolutely no feedback themselves. And yet one of them tells me, "We can just tell she's sweet. Often, their real personalities come out as they get older, only stronger. So if they weren't nice during their lives, they're even meaner now."

I'm not sure if I buy that, but I do know as I walk through the dining room, past the woman in the corner spewing nastiness at anyone who crosses her path; to the woman cradling a baby doll; as I listen to the man in his room shouting, "Help me!" and to the woman in the hall yelling, "Yoo-hoo," I am somehow glad my mother is the quiet one. And I know that, more than anything, that's the real reason the nurses like her.

Out of all the nurses we have come to know, it is a night nurse we do not who is holding our mother's hand when she dies. She tells us it was peaceful. I choose to believe her.

A bleeding ulcer and fever had weakened her in the final two weeks, and we knew the end was near. But I am still shocked. It is Aug. 14, 2007. My mother was 81 years old. And I never did tell her it was OK to go.

Months later, I panic a bit at the thought that my siblings and I are the caretakers of our family memories, memories that are so precious and yet so elusive that they evaporated from our parents' minds seemingly overnight. I wonder if I will forget. And then I close my eyes and I can still hear my father's voice. I know exactly what my mother would say. They can still make me laugh. And that will be enough.

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Behind the mask: Fear that it will happen to you too.

I am driving down a familiar street on my way to a familiar sushi restaurant in the neighborhood where I have lived for the last 14 years. I stop at the light and suddenly cannot remember which way to turn. Really can't remember which corner the restaurant is on. And it scares me.

I suppose if I can remember these things happening, then I am fine. But then that would be long-term memory, not short-term, wouldn't it?

My sister Susie calls me from Arizona. "I couldn't find my car today," she begins.

"Yeah, yeah, big deal, that's not Alzheimer's," I reassure her.

"No, I mean really couldn't find it, and couldn't even remember if I had driven it," she says. "I called the police, even."

"Oh," I reply, mumbling, "that happened to me once."

"Oh, yeah," she adds for emphasis, "I also wore my shirt backward one day last week."

"That's not Alzheimer's," I tell her, "that's just embarrassing."

My sister and two brothers and I are reasonably sure at least one of us will contract the disease that plagued our parents the last two decades of their lives. And because humor is as much a

characteristic in our family as blue eyes, we joke about it since there isn't anything else to do.

Currently, explains Dr. David Bennett, the director of Rush Alzheimer's Disease Center, there is no definitive screen for the disease other than using a battery of cognitive exams to document memory loss. And while scientists continue to experiment with various genetic and blood tests to predict who will develop Alzheimers, "most people in the field don't advocate people taking these tests outside of studies right now, so the real use for them will be when they're tied to some sort of intervention," he says.

Most people Bennett sees, like my siblings and I--those in their 40s and 50s whose parents have or had the disease--come in after living in fear for months and even years that they have Alzheimer's, he says, only to be tested and found they do not. But it is still better to be tested. "Worrying is bad for your brain," says Bennett. "That feeling of being stressed actually increases your risk of Alzheimer's disease."

I communicate this to my brother Barry. "Great," he says, "we're doomed for sure."

Since my parents were relatively young--late 50s, early 60s--when they first exhibited symptoms, our chances of developing the illness are higher than average. But everyone's risk increases as they age.

Of more constructive concern is the need for research funding and people to participate in studies, says Bennett, adding that President Bush was the first to cut funding for Alzheimer's since 1970.

The total National Institute of Health research budget for Alzheimer's is \$650 million and the current estimated cost to the economy of the disease is about \$148 billion per year and growing rapidly. "So you do the math," says Bennett.

Although there are currently 4.5 to 5 million Americans who have Alzheimer's and aging Baby Boomers will soon make it an epidemic, it is simply not on the national agenda. "I don't want to take anything away from cancer or heart disease to give to Alzheimer's," Bennett says, "but the heart, lung and cancer institutes are four times the size of the aging institute and Alzheimer's will soon be the most costly disease in the U.S.

"Unfortunately, with this disease, the outcry is not from people who have it. Breast cancer and AIDS patients have huge advocacy groups. People with Alzheimer's are sitting in the corner."

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