

# MOTHERS DAUGHTERS



# STRANGERS

What would you do if your mom was there...but not? For the who have Alzheimer's, this reality changes their lives—and possibility that they, too, could inherit the disease. *WH* explores

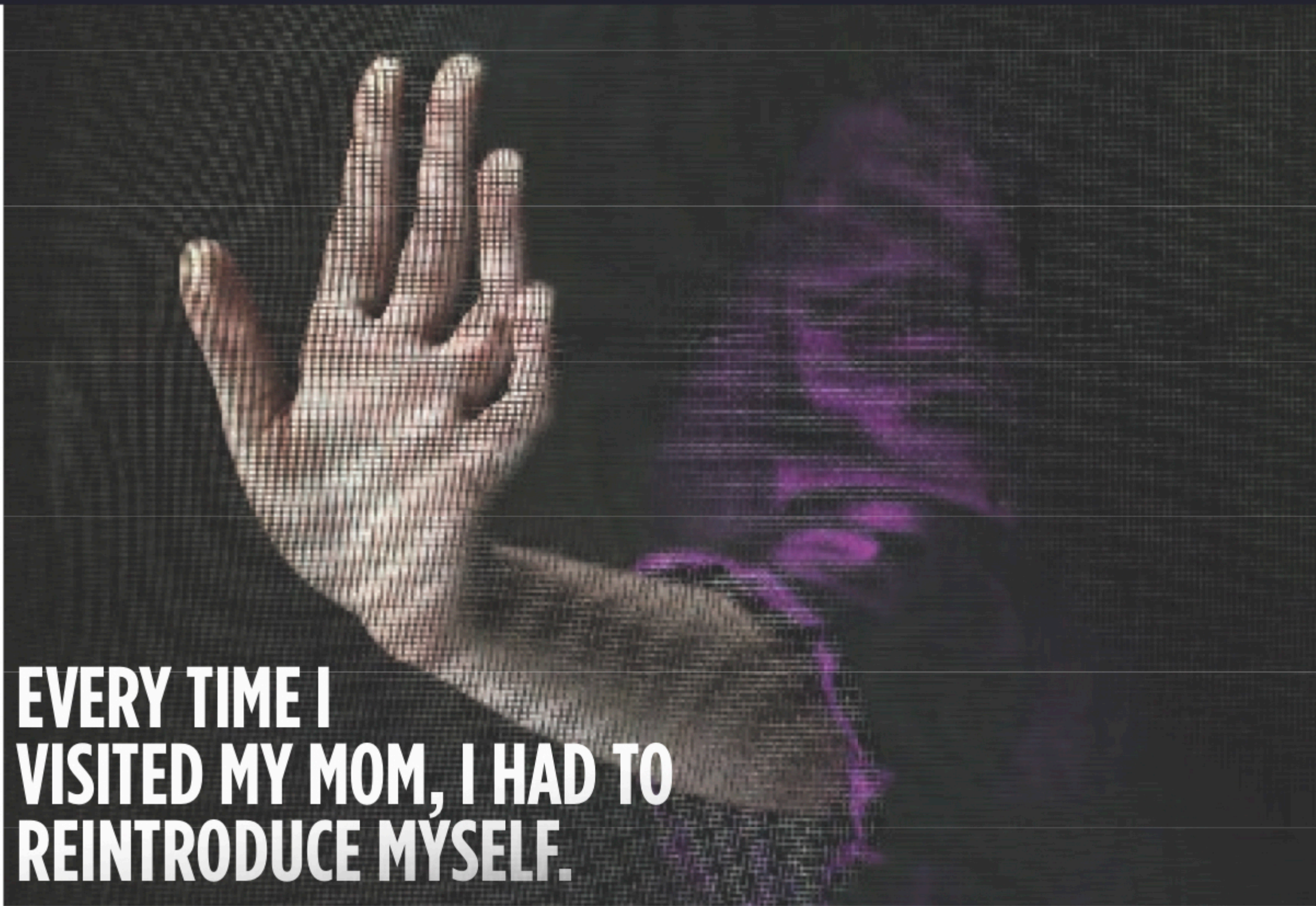
BY ASHLEY ROSS

daughters of the hundreds of thousands of people under age 65 their relationship with their mothers—forever. Just as grim: the the emotional and physical impact of the world's “longest good-bye.”

ELINOR CARUCCI, TWO EYES,  
1993/COURTESY OF EDWYNN  
HOUK GALLERY

# A WOMAN'S RELATIONSHIP WITH HER MOTHER IS INTENSE.

It's knotty, and enveloping, and complicated. And it influences her in ways she may not even realize. "Mothers are our primary role models, so a lot of what we learn about what it means to be a woman, we learn through our relationships with them," says clinical psychologist Roni Cohen-Sandler, Ph.D. As children, we worship the heroine who kisses away our hurts and rights every wrong; as teenagers, the bond can become more fraught or even explosive as we attempt to establish our independence. But then something beautiful can happen in our twenties and thirties—our connection to our mothers reaches a depth we never could have expected during those turbulent teen years. As we venture into the working world, develop serious romantic relationships, or have children, we learn to see our mothers as fellow adults with hopes, dreams, and struggles of their own. And yet as we forge our way, we still count on having our moms there to protect and support us unconditionally, as they always have. Now imagine losing all that. For the young women whose mothers have early-onset Alzheimer's—a form of the memory-destroying disease that strikes before the age of 65, and sometimes as young as 30—this newly created friendship and unwavering encouragement are



**EVERY TIME I VISITED MY MOM, I HAD TO REINTRODUCE MYSELF.**

stripped away, right at the time when their own lives have become ever more complex. "I just expected my mom to always be around," says 31-year-old Julie Scherr, whose mother died of Alzheimer's in 2014. "But for the three years before she died, she was a shell of herself. Every time I visited her, I had to reintroduce myself. Somewhere deep down she knew it was me, but we couldn't talk like regular mothers and daughters do." The distress is exacerbated by the fact that early-onset Alzheimer's has a genetic component—their mothers may actually have passed the disease on to them.

## Losing Me, Losing You

Three years ago, while her peers were knocking back shots at college parties, then-21-year-old Katie MacNeil moved home to take care of her 60-year-old mother, Andrea, who had been rapidly deteriorating since being diagnosed with early-onset Alzheimer's. The mother/daughter roles are now reversed: Katie helps Andrea get dressed (her mom has forgotten how) and reminds her to use the bathroom. "Sometimes she throws tantrums and says hurtful things, and I have to talk to her like she's 2 years old. It's a very out-of-body experience," says Katie.

Now 24, Katie is left with mere memories of the kind, capable mother from her childhood. "The only way I can cope is to remind myself: That's not my mom. It's somebody who has a very bad disease."

Alzheimer's is particularly devastating because the symptoms worsen for decades, as proteins called beta-amyloid and tau build up in the brain, tangling around its cells. As the brain cells slowly die, fine motor skills dwindle and memory falters. A sufferer may forget how to drive, speak, and, ultimately, even recognize her own child. "Alzheimer's is the longest goodbye," says 30-year-old Mackenzie Kelley,

## A Mother's Perspective

Two women—one with early-onset Alzheimer's, another whose daughter has a related disease—share their bittersweet stories.

### "I have Alzheimer's."

"When I was diagnosed in 2013, at age 65, our six adult children all stepped up. My three girls hired a cleaning woman for me because I forget to do regular things around the house, and they help me plan holiday meals, which will be of use to them when I can no longer host.

I'm so thankful for their support and the time we spend together, but it's hard to put into words how sad it is to not be able to do the things we used to do—I can't go clothes shopping with my daughters anymore because the many choices confuse me—and to see my memories just fall away. When my kids reminisce about the past, I have to fake it sometimes because I just can't remember.

My husband and I have found that a bit of black humor helps us cope. When we're all together, he says, 'We're making memories.' I joke, 'For who?' and he says, 'For me!'"

—Carole Poole, 68, Rockledge, Florida

### "My 7-year-old has dementia."

"From the moment my daughter Eliza was born in 2010, I daydreamed of the things we would experience together: watching girlie movies, proms, her wedding. Underlying all that, though, was just the longing for a special connection, the unique mother-daughter bond.

But when Eliza was 3, she was diagnosed with Sanfilippo syndrome, a fatal, neurodegenerative disease that's similar to Alzheimer's. It meant that Eliza—our joyful girl who loved to sing, count, and play dress-up—would lose her speech, her ability to walk, and eventually, her life.

That was four years ago. Her talking and singing are what I miss most. My daughter has dementia—her body continues to grow while her brain continues to shrink. We created the Cure Sanfilippo Foundation ([curesff.org](http://curesff.org)) and spent every moment, every ounce of energy of the last three years, working to raise money to fund research.

When Eliza was 6 years old, she was the first patient to receive an experimental gene therapy. Before the treatment, she hardly acknowledged my presence, but she looks at me now. I can see the 'her' that I thought was gone. I know she's still in there. We still don't know what the future holds, for Eliza or our family. I am hopeful; she gives me hope. But it still sneaks up on me in quiet moments that I am just a mom who grieves for what might have been."

—Cara O'Neill, M.D., 41, Columbia, South Carolina

## State of Affairs

As the disease progresses, you may need to make financial, legal, and health-care decisions for your mother. Enlist a qualified estate-planning attorney (find one at [naepc.org](http://naepc.org)) and a financial planner to help you through this checklist, ideally while your mom is still mentally strong enough to make her feelings known.

### Will or Revocable Living Trust

These contain inheritance instructions and appoint people to handle who gets what, when, and how.

### Directive to Physicians

This dictates general wishes about medical treatment, such as whether or not your mom would want to be kept alive on life

support. If she's in the late stages of Alzheimer's, consider adding a Physician Orders for Life-Sustaining Treatment (POLST), an end-of-life planning tool that specifies which life-preserving treatments (e.g., antibiotics, feeding tubes) can be used or withheld in an emergency.

### Power of Attorney

This puts you in charge of decisions about treatment, finances, and assets when your mother is no longer mentally or physically capable of making her own calls. You may face difficult choices, like which mementos siblings get, so be sure you're emotionally up for the task.

## The Progression

Some daughters find solace in knowing what to expect from Alzheimer's-related decline. While it varies by patient and typically progresses over a period of two to 10 years, this is the general course of the disease.

- Memory loss starts. The subtle moments of forgetfulness—getting lost while driving a commonly traveled route or losing track of important dates—are typical of somebody under stress, so may only be noticed in hindsight.
- Damage to brain cells makes it difficult for sufferers to express thoughts or carry out everyday tasks like paying bills. Moodiness can be common, especially in social situations or other mentally challenging activities.
- As the brain continues to change, motor neurons fail to send messages to the rest of the body, including the arms and legs. Writing and talking become difficult; walking becomes slower, or less controlled.
- Problems related to immobility and the basic functions of daily life lead to death. A common scenario: The patient no longer remembers how to swallow and can inhale food into their lungs, causing an infection that develops into deadly pneumonia.

CIG HARVEY

who was just 17 when her mom Carla was diagnosed at 52. “You can’t get to a point where you’re comfortable with what’s happening, because the next week something terrible could happen and she could need more care.”

Watching your mother’s physical and mental deterioration—often up close, since daughters tend to be the ones to care for an ailing parent—can give rise to a jumble of emotions, from sadness to anger and guilt. “In the beginning, I resented my mom, because I thought, *I’m so young, why should I be doing this?*” says Katie. Some daughters find watching their mother’s decline unbearable. “It’s not unusual for daughters to say, ‘This is so painful to watch. I just wish it was over,’” says Ruth Drew, director of family and information services at the Alzheimer’s Association. “Then they may feel guilty for having those feelings. But all of that is normal.”

The emotions are especially hard to cope with since most peers can’t relate. “All my friends’ parents had their wits about them. It felt like no one was in the same boat as I was, with a mother who was in a nursing home,” says Julie. “They were bonding with their mothers, while I was taking care of mine as if she was a child.”

### Fearing the Future

In lockstep with grief, young women must also grapple with the knowledge that, unlike late-onset Alzheimer’s, which is caused by a mishmash of genetic, lifestyle, and environmental factors, the early-onset form of the disease is nearly always linked to a mutation in one of three specific genes. (Researchers suspect the rare cases that don’t seem to be familial are caused by genes they don’t yet know about). Mothers who carry one of the known genes, which virtually guarantees the development of early-onset Alzheimer’s, have a 50 percent chance of passing on the abnormal DNA to their children, says James Noble, M.D., an assistant professor of neurology at Columbia University Medical Center and Taub Institute for Research on Alzheimer’s Disease and the Aging Brain. Meaning: Roughly half the daughters of early-onset patients are witnessing a preview of their own eventual decline, decades before it happens.

Jordana Koffler was 26 in 2009 when her 60-year-old mother, Bette, was diagnosed. “My grandmother died of Alzheimer’s in her mid-seventies, and my mom always used to say, ‘I hope I don’t end up like my mother.’ When she did, I remember thinking, *Is this going to*



**I REMEMBER THINKING,  
IS THIS GOING TO  
EVENTUALLY BE ME?**

*eventually be me?*” You can be tested for the genes that cause the disease (see “Knowing Your Risk,” at right), but since there’s no proven treatment to slow down Alzheimer’s, many women, like Jordana, decide not to.

Still, there is hope. Researchers are working on ways to delay the disease’s progression or even prevent it from taking hold in the first place. Along with a trove of studies that have linked diet and exercise to preserving memory, one promising drug has successfully halted the disease in mice and is now being tested in humans.

### Sense of Self

In the meantime, experts say daughters should focus on caring for themselves, not just their mothers. “Caregiving stress can take a toll on your emotional and physical

well-being, so self-care can be very helpful, even if you think you don’t need it or have time for it,” says psychologist Bonnie Gorscak, Ph.D., director of clinical training at the Center for Complicated Grief at Columbia University. Simple measures like taking a walk or meeting a friend for coffee can give you the mental breathing room you deserve. If you need someone else to step in and help, be specific (e.g., “Can you sit with my mom for an hour while I go to the store?”). Caregivers under 35 can also apply for financial aid to help pay for in-home care through the nonprofit group Purple Elephant (thepurpleelephant.org).

Some find comfort from other women who are going through a similar situation. Alzheimer’s support groups that are filled with elderly patients’ spouses can feel unrelatable, but Hilarity for Charity, a

nonprofit started by Seth Rogen and his wife, Lauren Miller Rogen (her mother has been living with early-onset Alzheimer’s for 10 years), hosts Google Hang Out Support Groups for young caregivers (hilarityforcharity.org). And the Alzheimer’s Association has a 24/7 hotline that caregivers of early-onset Alzheimer’s patients can call for decision-making support and guidance on issues like treatment options (800-272-3900).

Therapy—both traditional cognitive behavioral therapy and other styles—can also benefit daughters. Laurel Crosby, 30, who lost her mother, Joy, in 2015 after a six-and-a-half-year battle with

early-onset Alzheimer’s, says somatic-based movement therapy, in which an instructor has clients explore emotions through yoga and dance, helped her work through the feelings she had bottled up.

And as idealistic (and impossible) as it may sound, look for moments of pleasure amid the grief. “I like the saying ‘Cry when you have to, but laugh when you can,’” says Dianne Axen, R.N., a bereavement coordinator with Mayo Clinic Hospice. For Laurel, this was reading her mom the same books her mother had read to her as a child. “It was,” she says, “such a beautiful way to connect with her.”

Additional sources: Mary Sano, Ph.D., professor of psychiatry and director of Alzheimer’s disease research at Mount Sinai School of Medicine; Heather Snyder, Ph.D., senior director of medical and scientific operations, medical and scientific relations for the Alzheimer’s Association; Jill Goldman, genetic counselor at Columbia University Medical Center and Taub Institute for Research on Alzheimer’s Disease and the Aging Brain; Paul Viren, financial planner

## Knowing Your Risk

Seeing your mom fade from Alzheimer’s can bring up your own worries about developing the disease. Answers to common questions:

### My mom has it. Should I get tested?

If your mom passed on one of the gene mutations linked to early-onset Alzheimer’s, you’ll almost certainly develop the disease before you turn 65. Genetic testing is a personal choice that should be discussed with your family M.D. and a genetic counselor, but you may want to consider it if you’re thinking of having children. Purchase life insurance and long-term care insurance *before* the test; a positive result could mean higher premiums or denial of coverage.

### If I have one of the gene mutations, what can I do?

One large study found that after just two years, people with early cognitive decline who adjusted their diet (e.g., limiting sugar, avoiding saturated fats, eating fish twice a week); engaged in more social interaction (through group and individual therapy); controlled their blood pressure (evidence links brain and heart health); and exercised (strength training one to three times a week, and cardio two to five times a week) had up to 150 percent more cognitive function, such as improved memory, thinking, and processing speed, than people who didn’t make the changes. Researchers suspect results could be similar for early-onset Alzheimer’s patients.

### If I test negative, am I still at higher risk for late-onset Alzheimer’s?

Research hasn’t shown a definite link, but we do know that children of parents with the late-onset type are still at some increased risk for the early-onset variety, says Frank M. Longo, M.D., Ph.D., a professor of neurology and neurological sciences at Stanford University. And the opposite could be the case as well. ■