The Vanishing Family

They all have a 50-50 chance of inheriting a cruel genetic mutation — which means disappearing into dementia in middle age. This is the story of what it's like to live with those odds.

By Robert Kolker
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Barb was the youngest in her large Irish Catholic family — a surprise baby, the ninth child, born 10 years after the eighth. Living in the suburbs of Pittsburgh, her family followed the football schedule: high school games on Friday night, college games on Saturday, the Steelers on Sunday. Dad was an engineer, mom was a homemaker and Barb was the family mascot, blond and adorable, watching her brothers and sisters finish school and go on to their careers.

Barb was the only child left at home in the 1980s to witness the seams of her parents' marriage come apart. Her father all but left, and her mother turned inward, sitting quietly in front of the television, always smoking, often with a cocktail. Something had overtaken her, though it wasn't clear what. Barb observed it all with a measure of detachment; her parents had been older than most, and her sisters and brothers supplied more than enough parental energy to make up the difference. And so in 1990, when Barb was 14 and her mother learned she had breast cancer and died within months at the age of 62, Barb was shattered and bewildered but also protected. Her siblings had already stepped in, three of them living back home. Together they arrived at a shared understanding of the tragedy. Their mother could have lived longer if she had cut back on her drinking sooner or gone to see a doctor or hadn't smoked.

Six years later, Barb was 20 and in college when someone else in the family needed help. Her sister Christy was the second-born, 24 years older than Barb and the star of the family in many ways. She had traveled extensively as a pharmaceutical-company executive while raising two children with her husband in a nice house in a New Jersey suburb. But where once Christy was capable and professionally ambitious and socially conscious, now, at 44, she was alone, her clothes unkempt and ripped, her hair unwashed, her marriage over.

Again, the family came together: Susan, the third-born, volunteered to take care of Christy full time, and Jenny, the eighth, searched for a specialist (the family members asked to be identified by their first names to protect their privacy). Depression was the first suspected diagnosis, then schizophrenia, though neither seemed quite right. Christy wasn't sad or delusional; she wasn't even upset. It was more as if she were

reverting to a childlike state, losing her knack for self-regulation. Her personality was diluting — on its way out, with seemingly nothing to replace it.

What was left of Christy was chaotic and unpredictable. She refused to bathe and stopped bothering to make meals. She crashed a neighbor's party and made odd conversation with strangers. She clogged a toilet with tampons and flooded the house. She was gleefully impulsive, spending thousands of dollars a year on magazine subscriptions. That strange, reckless profligacy made Barb think of their mother, who in her final years sat at home, saying yes to every sales phone call. How heartbreaking but also interesting, Barb thought, that Christy shared the same peculiar tendencies — a family trait of sorts.

By 2006, Barb was long out of college, in her early 30s and married with two children, building a real estate career in Denver. One night, when she was putting the kids to bed, her phone rang. It was Mary — the fifth-born, 17 years older than Barb — in town unannounced. "Can you come pick me up?" she said.

Mary had always been one of Barb's favorite siblings. As a child she was a piano prodigy, precocious and outgoing, her gaze fixed on a future beyond her hometown. Mary grew up to be a mass-transportation engineer, consulting on projects from New Orleans to Abu Dhabi. She and her fiancé lived in Chicago, where Barb, then in her 20s, would visit, joining them for parties and nights out. But in recent years, things had changed for Mary. She was divorced and remarried with a young son, living in Omaha and only in occasional contact with the family. And here she was, where Barb lived, with no explanation.

Photo illustration by Najeebah Al-Ghadban

That weekend, Barb saw it all, the same movie playing again. Mary's affect was flat, far from the irrepressible sister she once was. Everyday courtesies seemed beyond her. She was in town for a work trip, she said, but hadn't bothered to book a place to stay or let Barb know in advance. When she talked about the project she was about to manage, it was with the language of a middle- or high-schooler, not someone with a master's degree and years of expertise. As soon as Mary left, Barb called Mary's husband, who was at his wit's end. Mary had never really bonded with their son, he said. She seemed disengaged from everything around her. The old Mary was disappearing, with nothing to replace her.

That's when everything cascaded for Barb. What the affliction was, exactly, she didn't know — no one did. But two of her sisters had the same thing that must have so drastically altered their mother.

This is genetic, she thought.

This is inherited.

And then, finally: *We all might have it.*

The others ignored Barb's concerns. It wasn't just that she was the youngest in the family and more easily dismissed. It was that a few years earlier, Christy had participated in some genetic tests with the University of California, San Francisco, that

had gone nowhere. Based on all the available knowledge about inherited brain disease, the specialist could not find an explanation for her changing behavior. But now Barb fixated on exactly what they were told — how the field was in its infancy and how just because they couldn't find a genetic marker didn't mean one wasn't there.

Barb decided to start a search of her own. She contacted the National Institutes of Health and learned about a condition that bore a striking resemblance to Christy and Mary's symptoms: frontotemporal dementia, or FTD, which emerges in the prime of adult life — as young as 40, in some cases — and relentlessly attacks the part of the brain responsible for planning, organizing, expressing language, understanding social cues and exercising judgment. Unlike more common brain disorders like Alzheimer's, FTD is confoundingly rare; researchers suggest that perhaps 60,000 Americans have it, though that estimate is complicated by how difficult it is to diagnose.

By the mid-aughts, researchers were still starting to identify and sort out the many varieties of FTD: Which were hereditary? Which weren't? How many were yet to be found? (Bruce Willis's family said they finally arrived at a diagnosis of FTD recently, after an earlier, provisional explanation of "aphasia," a condition that impacts speech, but have not disclosed whether his FTD is inherited.) The idea that the FTD field was still developing, and the knowledge base growing, only made Barb more determined.

In December 2006, she asked everyone in the family, including their father, to provide blood samples for a new round of analysis. Christy, Jenny and Susan agreed. The researchers failed to find any known FTD mutations — not surprising, in retrospect, given the limited number of samples. Barb's contact at the N.I.H. encouraged her to continue testing through the Mayo Clinic. The family remained in the dark, even as they watched Mary follow Christy's trajectory, losing all social awareness, defying common sense.

Then the following year, a new piece of information arrived from out of the blue, when Teddy — the seventh sibling, 11 years older than Barb — forwarded an email from a woman trying to track down distant relatives who might share the same medical problem her family seemed to be suffering from. The message included a photograph of the siblings' grandfather, a shared genetic ancestor on their mother's side of the family.

"We had no idea that branch of the family existed," Barb said. "I mean, it was crazy." The medical problem, the woman explained later on the phone, was FTD.

With equal parts awe and dread, Barb contacted the Mayo Clinic, which tested both families — two strains of the same gene pool. All of Barb's siblings participated this time, gathering there in person, as well as some adult grandchildren. With so many samples, spanning several generations in different wings of the family, the researchers

had a better trail to follow. Sure enough, the families had a mutation of the tau protein, which is now understood to be one of three major brain proteins associated with inherited FTD. “When they came in with the news, you could tell they were elated,” Barb said. “I think that’s how uncommon it is to find.”

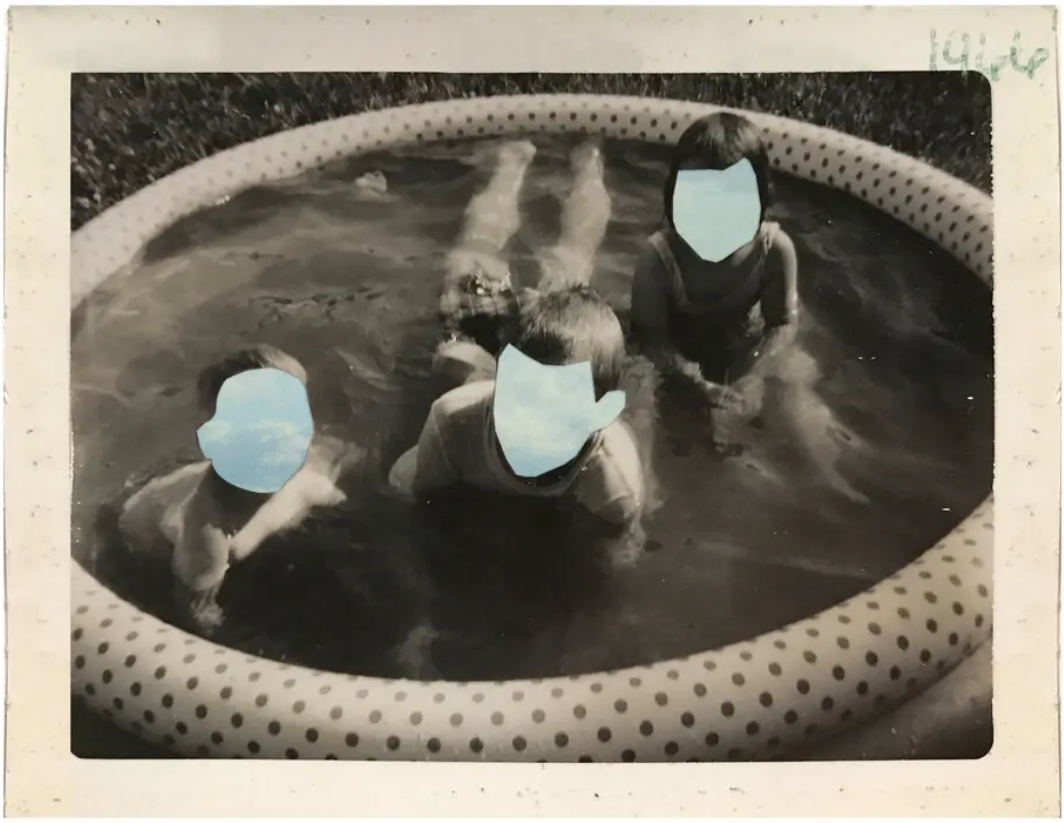

Photo illustration by Najeebah Al-Ghadban

Of course, it was also a catastrophe. There is no bright side to any FTD diagnosis — no cure, no path forward. With very few exceptions, everyone who inherits the mutation will, like Christy and Mary, long before their old age, develop inappropriate social behavior and lose the ability to earn an income, look after their children, do household chores or take care of their hygiene. They will eventually be unable to speak, feed or dress themselves or use the bathroom on their own. (This is the case with Christy, who at 71 spends most days in front of the TV and has an Apple AirTag clipped to a sneaker in case she wanders off.) The decline may be swift, but the end may not be: Unlike Alzheimer’s patients, who largely are diagnosed when they’re elderly, people with FTD can potentially live many years after becoming symptomatic, requiring decades of care. And their children — all their descendants — might carry the mutation, too.

As long as Barb didn’t know if she had it, she would try to live as if she didn’t.

Every sibling, except Susan, had children of their own. Kathy, the eldest, had a grandchild. They had all inherited, in essence, a coin flip — a 50 percent chance that they carried the mutation. Those who don't carry it are in the clear, and so are their descendants. Those who do will develop FTD, and they pass along that same 50 percent risk to each of their children. "I had a 4-year-old and a 2-year-old at that time," Barb told me, "and I remember thinking, I shouldn't have had my kids." She stopped short as she recalled this, then collected herself. "Which is, like, a very hard thing for a parent to think. It's a devastating feeling — that I may have passed something to them that could hurt them."

Even now, many in the family struggle with how to explain the impossible situation they've found themselves in. An earthquake or hurricane or war comes close — only a strange science-fiction version, something not visible or experienced by anyone but them; a disaster existing only inside their family's genetic code. There were the facts — *it's inherited, anyone might have it* — and there were the deeper questions raised by those facts. How do you feel safe, knowing that it is in your family's essential nature to be fragile, ephemeral, ever close to expiration? How do you keep living when you know that everything that makes you a conscious person could disappear? If you were going to lose yourself — in a year, or two, or 10 — would you even want to know?

Once the researchers found the mutation, they encouraged each family member to test at an independent lab to learn who carried it. Everyone in the family could discover which side of the coin flip they landed. But not everyone did. Teddy said he was never going back to the Mayo Clinic again, and he hasn't. Even Barb, who had been cajoling the others to get tested, could not bring herself to do so. Her future seemed like a forked road with no good options. Turn one way, you become, essentially, a shadow version of yourself, and everyone you love has to spend their lives taking care of you. Turn the other, and you still have to say goodbye, slowly, to some of the people you love the most. Why not do whatever you could not to engage in that strange binary choice?

And so Barb decided not to decide. She was 32 when the family learned about the mutation in 2008; even if she did have FTD, she most likely would not present symptoms for at least a decade. She would give herself until her early 40s to take action. "I figured, OK, I've got maybe 10 good years left," she said. Others in the family would take priority, for now. "The siblings I was closest with, they all raised me, practically, so my immediate concern was for them. Just, you know, how many more people am I going to lose from this disease in the next few years?"

As long as Barb didn't know if she had it, she would try to live as if she didn't. This was especially important to her because she spent her childhood watching her mother decline and then die. "I know that I did not grow up with a normal childhood," Barb said. "I wanted to give my kids as normal a childhood as possible. If I knew I was

destined to get this horrible disease, how normal would it have been?"

Of course, not being tested wasn't the same as not having the disease. How could it be? Barb entered a limbo, uncertainty hovering over her. Waking life became a continuous test of cognition, one chance after another to wonder if she was losing it. "Literally everything in a given day that goes wrong — if you forget someone's name, or you lose your keys, or you do something embarrassing — your mind instantly goes to 'This is it, this is the beginning, it's starting.' It just totally messes with you. It's exhausting."

She was vigilant in policing those thoughts, trying to keep the worst ones at bay, even shielding her husband. "He told me in a highly convincing way that no matter what happens to me, he's going to be with me until the end," she said. "But you know, there were a lot of times where I was dealing with that emotional stress alone, because I didn't want to burden him with it." Her husband, meanwhile, took action of his own — changing careers, training to be a lawyer to ensure he would make enough to support them. Only years later would they talk explicitly about what he had done. "It was a huge sacrifice that he made," Barb said.

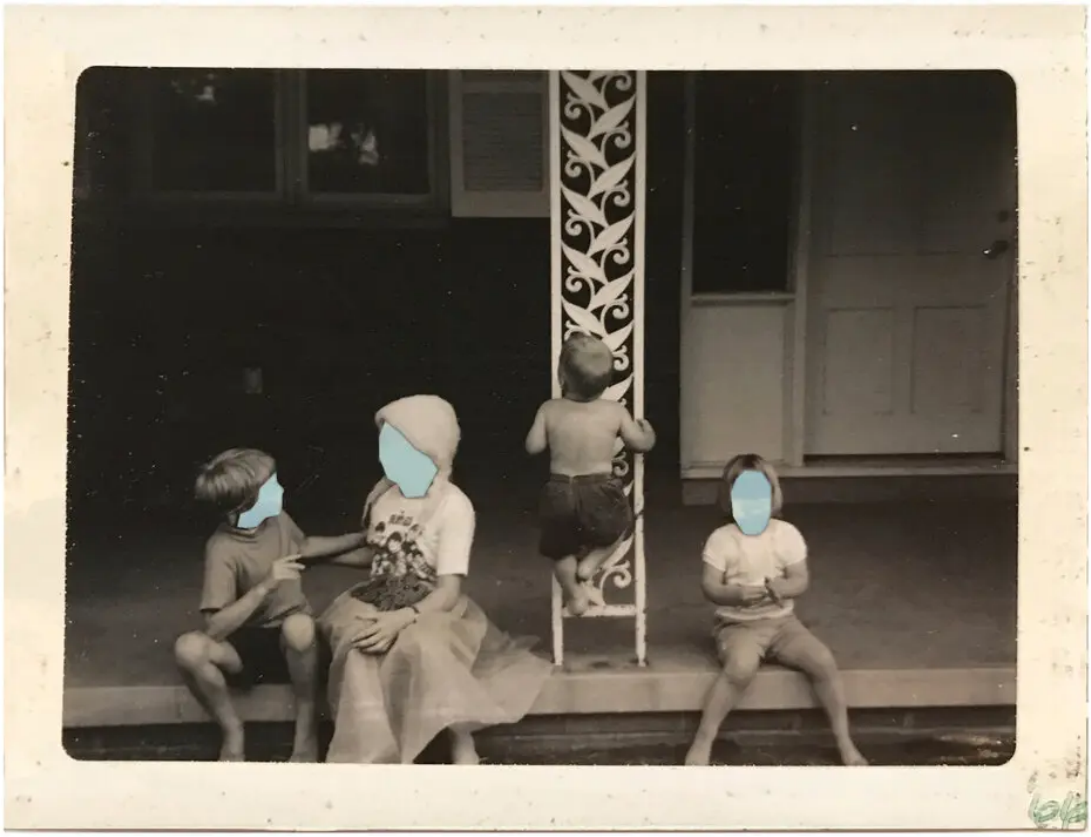

Photo illustration by Najeebah Al-Ghadban

As time went on and the pretense of normalcy became harder to maintain, Barb still tried to keep her children from hearing about FTD, even though they, like her, might possibly have the mutation, and even though it would be impossible to keep that information from them as they grew older. She also followed new research on FTD and Alzheimer's — two distinct diseases, each incurable, that attack brain function but with

remarkably different genetic properties — and fell into despair as no treatments for FTD emerged from that research.

Then, as Barb watched Christy and Mary decline further and two more sisters learned they had the mutation — Jenny in 2010, Peggy in 2015 — the sense that something was coming for her became impossible to ignore. In 2016, with her 40th birthday closing in, Barb became certain that she did, in fact, have it. She began bracing for the worst, living as if her days were numbered.

Eight years after the Mayo Clinic issued its diagnosis, Barb was tested, going in for the blood draw that would tell the story of the rest of her life. The clinicians required patients to receive the news, good or bad, in person.

But Barb never went back to hear the results.

Like Barb, Christy's daughter didn't want to find out right away. She knew there was a 50 percent chance of having it. Her mother had long succumbed to the disease, transforming right before her eyes. She was 12 when her mother's condition became impossible to ignore — when Christy stopped bathing or shopping or making meals. At the time, Christy's daughter, who asked to be identified by her first initial, C., was frightened, not least because of how alone she was: Her father was divorcing her mother and had moved to a neighboring town, and her brother was not yet 8, too young to register some of the things that she understood to be obviously wrong. Even now, she finds it hard to talk about that time in her life. "Driving home once with her, she got a flat tire, and she just kept driving," she told me. "I was like, 'Mom, you know, you've got to pull over.'"

It was up to her to raise the alarm with her father. "I remember a pipe burst in our house, and she didn't get it repaired. We didn't have water for days. I was just like, 'Dad, we can't live like this.'" The children moved in with him when she was 13, and Susan moved in with Christy. C.'s father has helped financially support Christy's care ever since.

Today, C. is protective of her father. "He tried to get her help," she said. "He had reached out to my grandfather, my mom's dad, and said: 'Something's wrong with Christy. Something's changing.' And he just brushed it off." She is equally protective of her own privacy. (She mentioned — and several others in the family told me this — that two of her aunts lost their jobs after speaking openly about their family's illness.) She is also charitable toward Christy. "I do remember her being a wonderful person, just fun and active," she said. But those happier memories seem less accessible to C. now, overshadowed by everything that occurred after the disease took over.

During her teenage years, she watched from a distance as her aunt Susan handled a host of challenges. Christy owed the I.R.S. $10,000 in back taxes. Christy ballooned to

250 pounds, until Susan finally padlocked the refrigerator. Once, Christy bolted from the mall on a shopping trip and wandered five miles in the cold and rain to a Wendy's, where the police were called and bought her dinner. Susan was in tears when she caught up with her, but Christy was fine — unfazed, even cheerful. During C.'s visits, she could see for herself her mother's mysterious, almost random new personality. Once, in front of C.'s boyfriend, Christy asked C. whether she was sleeping with David Hasselhoff, the star of "Baywatch," Christy's favorite show at the time. Watching her mother become so unrecognizable was excruciating. But with Susan looking after Christy, C. was at least free to be a teenager, to go to school, to one day start a life of her own.

Once she was in her mid-20s, building a career, that might have been that — her mother's tragic disease, a difficult childhood, a safe landing with her father. Then her family learned about FTD. While others, particularly her older relatives, lined up for genetic tests, she, like Barb, froze in place, deciding that she didn't want to know. She wanted to give herself time. "I was just like, 'If I find out I have this right now, I'm not going to have any motivation,'" she said. " 'I'm not going to have any desire to move forward.'"

She made a bargain with herself: She would be tested in five years, when she turned 30. For her, the decision to delay knowing felt less like denial than a play for personal agency, for control over something she had no control over. For those five years, C. worked hard not to think about the family's condition — to move forward as if it wasn't there. Pretending was even less possible for her than for Barb, when the example of her own mother was always present, directly in front of her, living with full-time care, losing her ability to speak, losing herself.

When C. turned 30, she had a boyfriend, a serious one, whom she told about the risk of FTD almost as soon as they started dating several years earlier. Now they were engaged. She went through with her plan to find out the truth. "I wanted him to have the choice to opt out if he didn't want to deal with me," she said.

They were together when she learned the news. Her boyfriend held her hand, no words passing between them. "I remember even the genetic therapist saying: 'You guys are just, like, such a great couple. I'm so sorry I have to tell you this.'"

C. approaches her life with a brass-tacks practicality. "Others have it worse than me," is a frequent conversational landing place for her, as is "It is what it is." After a childhood of instability and an adulthood of deep, pervasive uncertainty, she is determined not to waste energy on what she can't change or pull her focus away from a life she loves. She sees the world in this way, it seems, even if that means shaping complex situations in simpler terms — a sort of emotional firewall around the FTD diagnosis.

Her husband has become a good partner in maintaining that firewall. They were married, as they had planned. “He had already seen my family,” she said, smiling, “so I guess he kind of knew what he was getting into.” Together, they sorted through everything they could control. “We talked about long-term-care insurance and genetic testing for kids,” she said. “But I think we both understand that we can’t control the FTD aspect of things.”

After the wedding, they took time off and traveled. Better now than later, they thought. Just as she embraced living with her father when being with Christy became impossible, so now, in the face of something extreme, she clung to what happiness she could find.

When she decided to start a family of her own, they had a tool available for not passing on FTD: selective embryo transfer. C. could have her embryos frozen, and doctors could implant only the ones that did not have the mutation. More than a year of arduous procedures followed: fertility treatments and embryo retrieval followed by four attempts to implant, none of them successful. “My body did not like frozen embryos,” C. said. She was readying herself for another retrieval and a fifth implantation when she found she’d become pregnant naturally.

This, she told me, wasn’t planned — though given the difficulty they were having in conceiving, they weren’t inclined to be vigilant about birth control. She chuckled dryly when she told the story; a life filled with unexpected twists gets one more. She and her husband had all the obvious worries about the family mutation, but by then they had plenty of practice playing through those fears. Instead of fixating on what their child might inherit, C. thought about the clock ticking in more ways than one. She was 36, and after four attempts, it felt a little like now or never. With everything she had lived through and everything that was coming, she believed that good fortune was too precious to turn her back on. Who’s to say what other parents may be passing along to their children, genetic risks they don’t know about and that no one can test for? And more broadly: Isn’t she allowed to want this for herself? Doesn’t everyone have the right to a family?

Her aunts, uncles and cousins all had to be wondering about the genetic implications of having children. But the mutation casts a shadow over every interaction: Those who have it are too preoccupied to question the choices of others, and those who don’t feel too guilty to second-guess those who do. Barb, for one, has never broached the subject with C. “This disease brings up so many moral and ethical questions,” Barb told me. “I think all of us have tried to refrain from judging.”

C. now lives with her husband and son in a town not unlike where she grew up, where Christy raised her until she couldn’t. She is 40, about the same age her mother was when she first started showing symptoms. She sees Christy on holidays, visiting her

and Susan in Pittsburgh. The rest of her time is spent trying to have a life of her own. Her career is exciting, filled with problem-solving; every day at her job is different and distractions abound.

Once a year, along with many other members of her family, she goes in for testing to chart the progress of the mutation's effects: MRIs, blood tests, neurological exams, cognitive tests, behavioral tests, a lumbar puncture for brain fluid. Recently her doctor asked about her performance reviews at work. "I said, 'Well, I'm not trying to brag or anything, but they're always really good.'" The doctor's reply was sobering: "That's the first thing that's going to be a sign that you're getting it." She nodded. One more benchmark to consider, both useful and terrifying.

Barb had warned me about her sister Jenny. That she hadn't accepted reality. 'She thinks everything's just fine,' she said.

They have not tested their son for the mutation. That, C. told me flatly, will be his decision. "He'll learn eventually that there's a possibility," she said. "I'm not going to ruin his life, you know, worrying about this." And if her son is diagnosed one day? It's easy for her to daydream about new genetic editing techniques like CRISPR swooping in to save him with one simple, graceful, elegant snip — deleting the problematic mutation from his DNA. No cure is imminent, but that can always change, C. tells herself. "I think that in the next 30, 40 years, there's going to be a lot of movement on this stuff," she said. "I think he has a better chance than I do — and definitely more than my mom did."

Of course, it's probable that her son will be there to observe her changes, just as she observed her mother's. She and her husband have made arrangements, with her father's help, for any long-term care she'll need. Her genetic mutation clearly dictates certain things about her life, but she maintains she still has choices. Her choice is to decide — to insist — that her reality is not so different from others'. "Even though I didn't really have a mom, you know, I love my husband," C. said. "I love my child, I love my dog, I love my career — you know, I love my friends, I love my family. Am I going to focus on things that are bad?"

None of us know how our stories will end, she was saying, or what shape we'll be in by the time the end comes. "I guess another thing that I always kind of told myself growing up was that everyone is given a certain amount to deal with in life. And I'm dealing with it early, so the rest of my life is going to be great."

Barb had warned me about her sister Jenny. That she hadn't accepted reality. "She

thinks everything's just fine," she said.

Jenny is the eighth child, the sister closest in age to Barb, just 10 years older. For many years, she was an executive with a Fortune 500 company; she and her husband, Bill, who works in finance, lived in a town outside New York, where they raised two children. When Christy's life started to fall apart in 1995, Jenny was the first one there, cleaning Christy's house and finding a neurologist. Then in 2010, at 43, Jenny learned she carried the mutation, too.

She went on with life as if nothing had changed. She did not disclose her diagnosis to her children, who were still young. She told some relatives she was going to fight it, believing that changes to her lifestyle would stave off symptoms and save her from the inevitable. Scientists were close to a cure, she declared, though there was, in fact, no such thing on the horizon, which made some in her orbit wonder how far gone Jenny already was. But she was so determined to remain herself that she told her co-workers about her diagnosis — and lost her job soon after that. She hasn't been employed full time since then.

Jenny and Bill live in a sprawling home at the end of a long, wooded street. Over lunch, sitting next to Bill, Jenny was sunny and bright and chatty at first. She was happy to talk about FTD, about her siblings and about the mutation, but seemed unconcerned about the impact of the disease on her own life. She had successfully adjusted her eating habits, she explained, to avoid getting FTD. She was proud of the years she spent volunteering with an FTD organization, counseling family members of others who had been diagnosed. "I used to be the regional manager for this area — basically the Northeast," she said, "but then they switched it over to somebody else."

Before long, I noticed that Jenny was repeating a lot of phrases. Whenever a sibling had FTD, they were "out of their mind," like her sister Peggy, a former schoolteacher who used to play fiddle in an Irish-music ensemble and solve complicated mathematical equations. Now Peggy doesn't cook or drive and lives under the care of her longtime boyfriend. Jenny has often felt competitive with Peggy, and when she talks about her and some of the others, it is with an air of triumph. "I was the one who figured out that Mary had it, and I was the one who figured out that Peggy had it," Jenny said. "I could see their change in behavior."

I asked Jenny and Bill if they thought Jenny was fired in 2010 because of FTD.

"I think so," said Bill — thin and mild, with a soft voice.

Jenny interjected: "I don't think so. No. No, I was really good at my job."

"No, you were," Bill said. He sounded tentative, not sure of how to frame what he was going to say next. "But you know, they had this *potential* of your not doing well, further

on down the road."

"But I still don't have the disease," Jenny said, flatly.

Bill winced. And Jenny turned to me, smiled and shrugged, as if to say, case closed. "So, yeah."

Over time, as we spoke, Jenny's answers grew shorter, as if nothing we said was jogging new thoughts or leading her on new tangents. Even her gleaming smile started to strike me as limiting — not an armor exactly, but a reflex, a place holder for more complicated emotions. There seemed to be little behind it but a dwindling tank of memories.

But Jenny maintained she was fine. "I'm a superdeep sleeper," she told me. "What that does is it reduces inflammation of the brain. It *completely* reduces the inflammation of the brain. And so it keeps your brain really healthy."

She said she had proof. Each year, she is evaluated by the same specialists Christy and C. see. Jenny proudly showed me a printout of her latest cognition-test report. Bill seemed interested in the printout, too. I looked at the paper and saw several categories with the word "decline." When I pointed them out, Jenny just smiled and shrugged.

"It's not really in decline," she told me. "It's just like, my brain will play a game with me, and it, like, blocks memories sometimes."

I thought about Christy — how for so long she has seemed unaware of her condition, and how that is in some ways a blessing. Not realizing that dementia is creeping into your life is not the worst thing in the world. But for the people who love you, it can be not only horrifying but depleting — both watching a tragedy and understanding how powerless you are to stop it. Bill is at the precipice that the family crossed with Christy a long time ago. He struggles to find a gentle way to help Jenny, to correct her, without seeming overbearing or otherwise outing himself as the caretaker he has clearly become. But he knows that this is only going in one direction. Even if he did come clean about the progress of her disease, he wonders, what would change? "If she understands that something is a symptom, will it become less of an issue?" Bill said to me later, when we were alone. "I don't know."

Photo illustration by Najeebah Al-Ghadban

Jenny and Bill's daughter, Annika, uses a "Benjamin Button" analogy when she thinks about FTD: Whoever has it is aging backward, becoming not just dependent but transformed. Jenny had been a workaholic, competitive and hard-driving. After her diagnosis, she grew impulsive, just like the others. "She was drinking," Annika said. "It wasn't like she was an addict. It's like she just wanted to do it to have fun, and she wanted to be sneaky about it. She was acting like a teenager." Now, Annika says, her mother is consistently cheerful. *Everything will be fine* is Jenny's default position. She spends most days watching TV and shopping for food, visiting a number of different markets for exactly what she wants. Anything more complex than that seems beyond her.

Annika is in her mid-20s and living in another city, starting her life. She worries not just about her mother but also her father, who has health issues of his own. Who will care for her parents if he declines? That question helps Annika put off, for now, the decision she will have to face about herself — when to find out if she, too, carries the mutation. Like Barb, she wants to put off reckoning with her fate, in the name of preserving something supposedly more normal.

A few months after my visit, the family made some big decisions. Bill and the children decided that Jenny couldn't be home alone anymore. With Bill having to work at the office some days, he wants to hire an aide to watch Jenny. He made plans to put the house in a trust and give the kids power of attorney over his health and finances. He's

looking into taking Jenny to get her driving evaluated, with the hope that someone with the authority to tell her she can't drive will be enough to get her to stop.

Jenny has changed in the past months, too. She doesn't get upset or angry. "She's just, you know, communicating less," Bill said. "Often, she just doesn't respond at all." Still, Jenny doesn't believe she needs an aide, and it's hard to say how well she will listen to one. What will happen when someone tells her not to drive, and she decides to do it anyway?

"Well, that's a very good question," Bill said, his voice strained. "I mean, that just happened half an hour ago. She's at Walmart right now, buying groceries."

Barb was alone, standing in the front hall of her house, when the letter arrived on Sept. 26, 2017. The letter probably shouldn't have existed at all. In most cases, results this consequential are delivered in person. The author of the letter owned up to this — how normally this is against their lab's policy, but given the results, they felt Barb really needed to see it.

Barb had spent eight years not knowing, and a full year dodging calls from the lab since being tested. But this envelope was thick enough to prompt the thought, drifting in out of nowhere, that maybe she shouldn't just throw it out.

Even as she opened it and started reading, Barb remained convinced of what it would say and what that would mean for her and everyone who loved her. "It didn't ever occur to me," she said, "that I might get good news."

There was, at first, a wave of disbelief. Then a call to her husband, which made it more real. The two of them cried together over the phone. That night, they told the kids everything. They were 13 and 11 at the time. They knew some of their aunts had problems, but they were never told what they were, and they had never asked. Barb sees now how strange that must have been for them to learn about an illness that others in the family would get, but not them. "We made them drink Champagne with us," Barb said. "So they were like, 'Cool, we get to drink Champagne.'"

It has been a few years since that toast, enough time for Barb to think about the years she spent putting off knowing. While she understands why she did it, she also now sees how even the possibility of having FTD had changed things for her, limited her world, blunted her ambition, blotted out her sense of what was possible for herself and her family. She thinks of moments at work where she didn't raise her hand, didn't try to accomplish more, didn't want to assume authority because of the illness she might have, the symptoms that might emerge any day. Would she have asked for more, expected more, if she'd been tested?

"I think it probably held me back from applying for leadership positions because I was

nervous that maybe I wouldn't be able to finish the work or stay in it, make a multiyear commitment, because what if this disease sets in?" she said. "I think it was all happening on a very subconscious level. It wasn't until I found out that I didn't have it, and all of a sudden, I felt so confident in myself. And that's when I realized that I had been feeling really unconfident for 10 years."

She sees how terrified she had been not just for herself but for her husband and children, the responsibilities they would have had to shoulder in caring for her — to say nothing of the possibility that her children would also have the mutation. Now came the strange feeling that all of that, everything she'd been negotiating in silence for so long, had passed them all by, like watching another car on the highway hop the guardrail and crash.

Next, for Barb, came the guilt, and with it a sense of obligation. Instead of worrying about her own mind and her children's, Barb spent her days thinking more about those in her family who were suffering. "It was hard to talk about me not having it with my siblings," she said.

Of the nine brothers and sisters, five now have active signs of FTD: Christy, Mary, Jenny, Peggy and Oliver — the fourth-born, four years younger than Christy — who had been behaving strangely for many years until, in his 60s, he dropped out of sight during the pandemic, homeless and off the grid for more than a year. These were people who, decades ago, had come to care for Barb when she needed them the most, when their mother died. What will happen to them? Whose responsibility were they now?

"I had thought long and hard about what's my job here? What's my role in the family?" Barb said. "Maybe if there was one sibling for me to care for, I could do that. But now I'm looking at five, potentially. How could I possibly take in five FTD patients? And if I want to help one of them, how do I choose?" Barb wondered whether the family could chip in for a compound somewhere — a place where everyone could care for one another, pooling resources. It seemed too complicated to pull off, with so many siblings having to uproot themselves.

There are also some who probably wouldn't want to be helped, including Oliver, who worked as a trucker for years, until he started having trouble holding onto a job. Like Mary, he developed a habit of dropping in unannounced on relatives all over the country. Oliver is now in assisted living. When he resurfaced at a hospital last year, Susan and a nephew drove 22 hours to bring him to Pittsburgh, and Barb navigated the Medicaid bureaucracy to help find him a place. His adult daughter, Mallory, had persuaded him to grant her and Susan power of attorney a few years earlier. But lately he has been turning away visitors. It's unclear if he is upset about being there or if his dementia has simply entered a new phase. Susan dropped off Christmas cookies, but

he would not come down to accept them.

Mary's life also seems unsettled. While Christy has become more docile over the years, the family has watched as Mary became more confrontational and even paranoid. She divorced a second time and is now living with her third husband in the Pittsburgh area. She has stopped returning calls from family members or going to medical appointments with them; they have no way to know what kind of care she is getting. (Three of the nine siblings — Teddy, Mary and Oliver — did not participate in this article.)

There's a way in which the entire family has rearranged itself around the disease — some drifting away geographically, others fading away cognitively and still others who are unscathed, desperately trying to hold it all together.

Last Thanksgiving, 15 members of the family gathered in the Adirondacks at a rented lodge with a vaulted-ceiling living room and massive stone fireplace — a family compound, at least for a few days. Barb and her family were there, as was Kathy (the oldest sibling, who doesn't carry the mutation) and her son Charlie (also free of the mutation), along with his wife and son. Jenny and her family were there, too. Barb's children had not seen her in a while. Barb kept an eye on them, noticing them noticing the changes. "They're finally seeing what I've been dealing with for 20 years," Barb said — the siblings who are afflicted and the sense of responsibility that carries.

Susan drove eight and a half hours with Christy beside her. In the lodge, most of the family played games while Christy sat in a soft easy chair by the fire, beaming at everyone. "I think she enjoys seeing other people and different faces," Susan told me a few weeks later, "just because I'm the only one that she sees most of the time."

"I believe she remembers us," said Kathy, who lives an hour or so away from Christy and is an occasional backup for Susan. "I believe she recognizes us."

This will be Susan's 27th consecutive year as Christy's full-time caregiver. When Susan started, she was barely out of her 30s, single and between careers. She did not expect her life to take this turn, and in all this time, she has demonstrated a capacity for forbearance that others in the family freely admit they lack, a sort of secret reservoir of equanimity she can draw from in times of trouble. "Susan always saves the day in our family," Barb told me. Remarkably, Susan has never been tested for the mutation. She, too, put off the decision for years, until finally, at 67, she assumes she simply does not have it. Instead, she remains focused on caring for her sister.

Every morning, Susan rises early, pulls the laundry out of the dryer, tees up all the meals for the day and makes herself some coffee before waking Christy. When Susan coaxes her to the toilet and then to the shower, things go more smoothly when they sing. The morning I visited, it was "Do You Want to Know a Secret," by the Beatles.

“She knows the words,” Susan said, though the most Christy offered up during my visit was a high, boisterous humming noise, on pitch.

While Barb closely follows the progress of scientific research into FTD, Susan is the emotional glue of the family now, staying close not just with siblings but with nieces and nephews who are willing to help when they can. Over dinner, Susan reflected on her time with Christy, but only in fits and starts. “I’m not a saint,” she told me. “This is devastating.”

When the talk shifted to Christy’s doctors, the conversation slowed down. There was something they weren’t saying. Finally, Susan came out with it.

“Christy has breast cancer,” she said — just like their mother. “That started about a year and a half ago. There was a sore on her breast. And I just decided, you know, we’re going to let it go.”

Susan was grave when she discussed what that means — how wrangling Christy into a cancer-treatment regimen seems too much to ask of her. So they’ll continue together for as long as it takes. They had understood for a while that the genetic mutation that took over Christy’s life may not be what would take that life away. Now, after all this time, they know how her story will end.

Robert Kolker is a writer based in Brooklyn. In 2020, his book about a family’s struggle with schizophrenia, “Hidden Valley Road,” became a selection of Oprah’s Book Club and a New York Times best seller. His last article for the magazine was about Joshua Spriestersbach, a man mistakenly held at a state mental hospital for more than two years. **Najeebah Al-Ghadba**n is a collage artist who, through the cutting away or transfiguration of images, focuses on how much we reveal or conceal about our internal worlds.

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