

The Never-Empty Nest

As the clock ticks toward the future, everyone in the family wonders: What will happen to “the boys”? By Michael Callahan

My sister-in-law Jean is 50, and pretty in that Sarah Jessica Parker way: trim, stylish but not style-obsessed, great smile. She and my brother Pat have been married for almost three decades, and they have two sons: Matt, 26, and Sean, 23. They live in a nice suburban house, and have a small beach condo they go to on weekends. But Jean also has the biggest burden of anyone I know.

When they announced they were pregnant in the fall of 1984, I was as thrilled as anyone. Matt, as a toddler, charmed all of us with his mop of blond curls and wolfen-gray eyes. Still, almost from the start there seemed to be something...off. He didn't crawl, he had difficulty taking a bottle, he couldn't seem to focus on tasks. At the age of 2 he was diagnosed as having special needs. The doctors told my brother and sister-in-law to have another baby; it was their feeling that a sibling would help Matt developmentally. So they did. In 1988, Sean came along—like Matt, a baby straight off the Gerber label. Only Sean turned out to be more disabled than Matt. And that was when we knew that all of this was not just coincidence.

In 1990, Pat and Jean stood in a hallway at Children's Hospital of Philadelphia and learned the awful truth: Both boys had a form of autism caused by a then newly discovered disorder called Fragile X syndrome, which would keep my two nephews in a state of suspended toddlerhood until they were old men. For the rest of their lives, the boys would be wholly dependent on their parents or other adult caretakers.

The condition manifests itself differently in each son. Although both share some mannerisms common to autistics—the holding of their ears, the nervous hand

movements, the inability to focus on anything for more than a few seconds—they're also different in key ways. Matt has more of an ability to absorb what you're saying and even occasionally reply, though he's tough to understand. But he's very anxious, and can't stand being around a lot of people. He's also obsessed with food—when he's eating, what he's eating, and how quickly he can eat it.

Sean, on the other hand, is more manic, constantly jumping around excitedly. Of the two, he seems more faraway in his look. He doesn't speak—at all—he's not fully toilet trained, and in 1998, at the age of 10, he was diagnosed with acute juvenile diabetes. For a boy (now a young man) who basically only eats three things—soft pretzels, toast, and waffles—all of them loaded with carbohydrates, that's been almost as hard to manage as his disability. Jean's life, already rivaling Job's, became a whirlwind of blood-sugar readings and insulin shots—five injections a day—all dutifully recorded in the grammar-school copybook she still lugs with her everywhere to track how to keep her son alive.

Our view of disabled kids is a skewed one. A young child with a disability takes on the aura of a damaged teddy bear. We see their stories gauzily packaged as Hallmark Hall of Fame specials. Indeed, when Matt and Sean were young and still eligible for special school programs, it was easier: The boys had speech therapy and music therapy and swim therapy to keep them occupied. But at some point even the most disabled kids age out (typically at 21). When the boys were in their late teens, Jean looked into day-care programs for developmentally disabled →

Photograph by Ryan Donnell

After Sean was diagnosed,
Jean decided to follow one mantra:
“I never think past dinner,” she says

young adults, but found nothing but fluorescent-lit, dirty rooms filled with screaming adults and caseworkers either sleeping or overwhelmed. So when Matt and Sean finished school, she did the only thing she could do: She kept the boys home with her, full-time. And now each day, every day, she takes them along—to the supermarket and the mall, to hair appointments and doctor’s visits, weaving in and out of gawking passersby.

Nobody talks about what happens when the adorable kids grow up, as Matt and Sean did, to be clumsy, awkward adults. Or what happens when one of them, at six feet and 200 pounds, has a meltdown in the middle of a shopping mall and plops down on the floor, refusing to get up and attracting a huge scene, as Matt did when he was 19. Or what happens when the other son, a nonverbal diabetic, escapes from the backyard at age 11 and wanders off, setting off a county-wide manhunt that involves squad cars, emergency vehicles, and a police helicopter. (It turned out Sean had meandered into a neighbor’s house, switched on the TV, and sat down to watch.) It’s not all quite so adorable then. It is hard. It is wearying. It is, in a word, relentless.

Recently, I asked Jean what she wished people understood about her life. She told me: “That it’s busy, tough, and exhausting. Parents get feedback from their kids 24/7; I don’t. Most kids can entertain themselves for long periods; mine don’t. Sean has the hyperactive aspect of Fragile X, and Matt has the anxiety aspect. Trying to keep Sean active and Matt calm—and not eating—is a full-time job. And my day is chock-full of guilt. Not because they have Fragile X, but because I never seem to be able to do all of the things I think I should do. I don’t do enough



housework, I don’t do enough with the boys, I don’t take care of my parents enough, I don’t call my friends enough, I don’t do enough for myself.” Luckily, she says, at night she’s so wiped out she doesn’t care anymore. “And there is always tomorrow.”

I find my sister-in-law extraordinary. And inspiring. And tragic. Sometimes all I can see is what she doesn’t have. She will never watch her sons graduate. Never dance with them at their weddings, or be blessed with grandchildren. Does it pain her to raise two sons, devote her life to them, and know that neither of them will ever throw his arms around her and say, “I love you, Mom”? Yes. Does she ever wish she could get one—just one—night of uninterrupted sleep? Yes. But she made a decision after Sean was diagnosed, and she has stuck to it. And that decision is to follow one mantra in order to keep herself upbeat: “I never think past dinner,” she says.

And still I know that she would no sooner trade in her kids than throw herself into a ravine. Fragile X testing is now done in the first trimester of

pregnancy, though in Jean’s case, she would never have terminated.

I think that is what eats at her the most: the way people look at her, how she suspects that deep down they are all thinking the same thing: *Don’t you wish you had known, so you could have aborted?* Her answer: No. A sentiment I know my brother shares just as deeply. “We were meant to have Matt and Sean,” she says, and I believe she means it.

Of all the things I don’t understand about Jean, I have to admit that her faith—fierce, firm, enormous—may be the most enigmatic. (I call her “Jean of Arc.”) I admire it tremendously, and I feel bereft because I can’t access it. But I can’t ever seem to get past the question it always brings up for me: *How can you put your faith in a God who would hand you such a rotten deal?*

She told me a story recently. Raised Methodist, in 1998 she had converted to Catholicism, which is the faith Pat and I were raised in. That was when Sean, at age 10, fell ill and was diagnosed with what was →

then a life-threatening case of juvenile diabetes. He hadn't slept in two days, was violently sick, couldn't eat. Terrified, Jean stepped into the hospital chapel and fell to her knees. *OK, she prayed. I accept this, but I cannot do this alone. I need help.*

Sean got better. Ever so slowly, Pat and Jean began to master the arcane process of monitoring his blood sugar. And Jean's bubbly Aunt Pearl, armed with an infectious cackle and a laundry basket of can-do spirit, took a class in diabetes care so the two could actually go away for a weekend once a year.

My brothers and I have come up short, perhaps out of fear of getting sucked down the rabbit hole

Jean has fought to cobble together some semblance of a normal life, scheduling the odd girls' night out and volunteering as a Catholic-education teacher on Wednesday nights to force herself out of the house. As their family, I know the rest of us should do more. Aside from Pearl, I'm afraid we have come up rather short—perhaps out of an unspoken fear of getting sucked down the rabbit hole of their difficult lives. Because there will never be that day when my brother and sister-in-law turn the boys' lives over to them, when they go out into the world on their own and Pat and Jean stay behind on the porch, promising to be there if the boys need them but knowing that from here on out, it's really up to Matt and Sean to be who they will be. Instead, there is just the constant hum of worry.

That is the part I can't see, that she won't let me see—the part I wonder sometimes if even my brother sees. The mother who stares up at her bedroom ceiling in the middle of the night, even though she is dead tired and one of her grown sons will be in

at any minute to kick her out of her own bed because he has just wet his. Who asks the most terrifying question a parent can ask, the one all of the praying and baking and scrubbing and bleaching can't help her outrun: *What will happen to my boys?*

There's a five-year gap between my brother Pat and me; he is stationed just above me in the pecking order. That gap, along with the fact that I was artistic and sensitive in a family where those qualities weren't always viewed thoughtfully, made

me feel faintly like The Other during my working-class Philadelphia childhood; I was au gratin in a family that was firmly mashed potatoes. Perhaps sensing this, when I was 11 Pat began hauling me away from in front of the television set to his school-gym hockey games.

By the time Jean showed up three years later, Pat and I were really close, and mercifully, as his girlfriend, she not only respected our relationship but also encouraged it, a gift that has been a constant in the 30 years since. She was truly the sister I'd never had, and over the years I came to trust her advice and lean on her love and laughter as much as I did his. She never seemed to let life rattle her, something I looked at with utter amazement as I sweated every test score and bad date. She and Pat were married on a stormy spring Saturday in 1983, everyone dutifully chiming in about how the torrential rain meant good luck. Only it didn't.

Yet somewhere along the line, my brother and sister-in-law decided that wallowing around in the might-

have-beens wasn't going to give the boys what they desperately needed, which was love, structure, and a sense of family. As Pat has often said, "The cards get dealt, and you play the ones you get." Still, very few people are dealt a hand like this. My brother took a killer, stress-level-10 job in the Philly suburbs so they could afford for Jean to manage the home front full-time; she'd planned on being a stay-at-home mom, at least while her kids were young, but any thoughts she might have had of picking up a career when they were older vanished.

Having disabled kids also makes you realize that you need to indulge yourself sometimes. Three years ago, Pat, Jean, and I went in together and bought a place along the New Jersey Shore. Nothing fancy, just a three-bedroom condo two blocks from the ocean, but a piece of heaven to us. I love the beach. Always have. But we really bought the place for the boys.

Both love it there. Matt will stand for hours, looking out onto the water; Sean will run up and down the coastline, almost inexhaustible, a huge grin on his face, occasionally dragging my brother down to the surf to sing a song from the Disney canon. I've grown into something of an add-on to their tight nuclear family, the bachelor uncle available both to lend a mostly ineffectual hand and—mainly, I think—to provide Pat and Jean with a link to the world outside their time warp, in which the boys are always, well, boys.

We have settled into a routine on our summer weekends at the shore. Jean feeds the boys early Friday night, and then she and I eat with Pat when he shows up later, after the boys are in bed. With disabled kids, routine is everything. It's the only way you make it from one day to the next. →



To make you smile

The Gap Year

By Sarah Bird

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To curl up with

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By Bobbie Ann Mason

A pilot shot down over France returns years later to search for the *jeune fille* who rescued him. Mason's lovely tale, drawn from her father's wartime experience, will resonate for many.



For a touch of glam

The Memory of All That

By Katharine Weber

Weber's family boasts a slew of characters: Grandma was Gershwin's mistress, while a granddad inspired *Annie's* Daddy Warbucks. This rollicking memoir does them all justice.



For a heart tug

The Summer of the Bear

By Bella Pollen

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Sometimes Sean won't eat when he needs to—which, with diabetes, can spell major trouble. So you develop crutches. In Sean's case that means music: a portable CD player he can amuse himself with at the dinner table. It helps. It also drives me insane. Because he won't listen to a song; he'll listen to a *verse*—sometimes just a phrase—and then rewind it, over and over and over, until your ears bleed. Have you ever listened to the lyric “You're my little chu-chi face/And you're my teddy bear” from *Chitty Chitty Bang Bang*? I sure have. Once, 87 times in a row.

One day last summer Jean and I were in the kitchen when Sean started up with the rewinding thing. And after the 55th—maybe the 56th—playing of Uncle Remus singing “zip-a-dee-doo-dah,” I cried, “Enough!” I was half-joking, but the half that wasn't won out. Humoring me, Jean unplugged the CD player. Mercifully, Sean ate the rest of his soft pretzel and all was peaceful with the world.

“I'm sorry,” I said, before blurting out, “But honestly—some days don't you just want to throw the CD player out the window?” I was asking a larger question. I was asking the question everyone who ever meets Jean never gathers the temerity to ask: *How on earth do you do it?* She shrugged and smiled. “I do indulge them,” she admitted. “I work to make their lives good now, because I know their lives won't be good later.”

Though I know they've discussed their situation with their priest and doctors, the truth is that Pat and Jean don't talk about the boys' disability that often. But they worry, and they suffer, in an acute way that my other brothers do not about their children.

Fifteen years ago, there was a reunion of Pat's old street-hockey league, and as the former mascot I went, too. Seated at a long table in a local pub, we talked about the “old days,” which

weren't really all that old, and we laughed and told stories and drank beer. There was a jukebox in the place, and someone played Louis Armstrong's “What a Wonderful World.” Sitting across from me, Pat leaned over and said, “This song always reminds me of my boys.” And as I listened to Louis's soothing recitation of all the things that make life worth living, I watched, stunned, as my brother slowly dissolved into tears and his friends continued laughing and carrying on, oblivious.

He shielded his eyes so no one could see. I couldn't move, knowing that he would kill me if I made any overt effort to comfort him. And so I sat in the noisy taproom, watching my brother sob for his sons.

Of course, Pat and Jean are doing their best to ensure that the boys' future will be the best it can be. They've set up a trust fund for their long-term care, and I share their optimism that my brother Tom's four fine sons—now 20 through 26 and including a medical student and an actuary—will step up as their cousins' legal guardians later in life. The current plan is that Matt and Sean will live with their parents for as long as possible, and when Pat and Jean are too old to care for them alone, they'll hire a home health aide to come in daily. After either Pat or Jean dies, the surviving parent will transition the boys into a group-living situation. And the indulgences my sister-in-law shows them both now will end then.

“I do worry about the future,” Jean told me recently. “I worry about the physical problems Sean could have due to his diabetes. I worry about him being in a hospital with no one to be with him. I worry that if they live in a group home after we die that workers won't be nice to them—especially on a bad day, when even I tell them I →

want to kill them. And *I* love them.”

Tom’s kids, she says, have assured her they’ll be there. But who knows what life has in store for them? Is it fair to expect a young man *not* to take some great job in California so he can look after his two adult disabled cousins back home? “The best option for us,” Jean says, “is to stay healthy, check out options for them as we get older, and pray.”

I once asked her what advice she would give a mom who had just found out that her child had been diagnosed with Fragile X. “I would tell her that you have a child who will never hate, argue, or disappoint you, and whose love is unconditional,” she replied. “At night, when we tuck the boys in, you see how much love they have in them. Matt, at his greatest comfort level when you lie down with him,

confirms the plans for the next day, then tells you that he loves you and to get out. Sean lies in his bed, eyes closed but not really asleep, with no pillows—a Sean rule—and you kiss him good night and tell him you love him. Without opening his eyes, he smiles. That’s what matters.”

Perhaps it’s all that matters. But still I wonder what it will be like when Jean is a silver-haired old woman, hugging her boys good-bye at the door of some group home when she can’t take care of them anymore. If watching my sister-in-law deal so absolutely extraordinarily with her ordeal has taught me anything, it is the power of now, the beauty of seeing things as they are, not as you wish them to be. She adamantly refuses to live a life of “if only,” wrapping her arms around what is. Through her and Pat, I have

been able to see what they see, which is the sheer goodness of the boys, what it is to walk through life unjaded, content simply with being. In their emotional purgatory, the boys exist happily in lives not measured in ups and downs or months or years, but in moments: the joy of a song, the feel of an ocean wave cresting over feet, the sheer yumminess of a hot pretzel.

Sometimes, to get through the days, you have to look at your boys and not see what is wrong but instead insist on seeing what is right. Like Louis Armstrong, you have to see skies of blue and clouds of white and think to yourself, *What a wonderful world.* ■

Michael Callahan is deputy editor of Town & Country magazine. For more on Fragile X syndrome, visit fraxa.org.

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