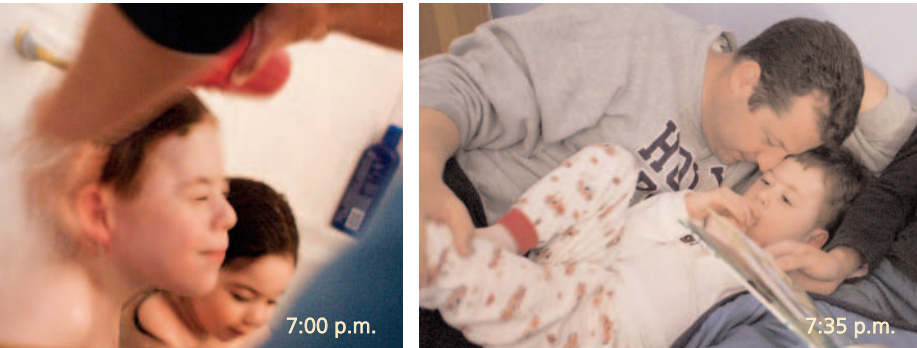


## getting to bedtime

They're the witching hours for most of us—only more so for the Foard family.

BY CHARLOTTE MERYMAN   PHOTOGRAPHS BY MOLLY LAMB



The series so far: Michelle and Jim Foard have a son, Jimmy, 5, and a daughter, Maddie, 2. Jimmy was born with Alfie's syndrome, a rare chromosomal disorder in which part of the ninth chromosome is missing. He also shows about half the signs for autism. In Part 1, Jimmy navigated the minefields of an average birthday party. In Part 2, we watched him struggle to speak his first words. Throughout, the Foards have shown us that to be Jimmy's parents is to embrace "a different kind of perfect," as Michelle says, and "a different kind of normal."

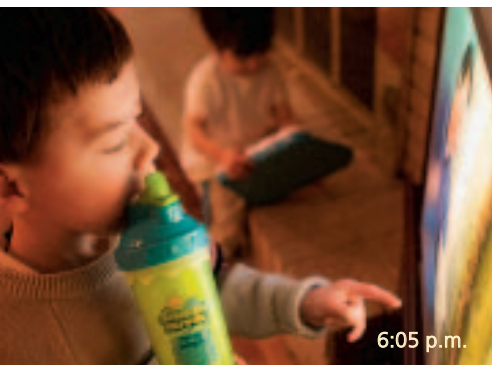
**6:15 p.m.** Jimmy Foard is scootched up to the kitchen table, picking at spirals of take-out macaroni and cheese. His sister and his parents dig into their own dinners: more noodles, a meatball panini, a mini-pizza. Supper is late, thanks to Jimmy's weekly music therapy class. Everyone is a little weary. Jimmy gazes hopefully at his father. "*Kuh, kuh, kuh,*" he says. "No, Jimmy, no computer now," says Jim. "Finish your dinner." He takes Jimmy's fork, spears several noodles, and sets the fork in front of his son, who reflexively lifts it to his mouth.

Around them, the room is in mild chaos. Books and papers are piled high, the walls mostly bare. After eight months, the Foards are still settling into their new home, a fixer-upper not far from their old house, in Longmeadow, Massachusetts. They moved in part for Jimmy to have a nice yard

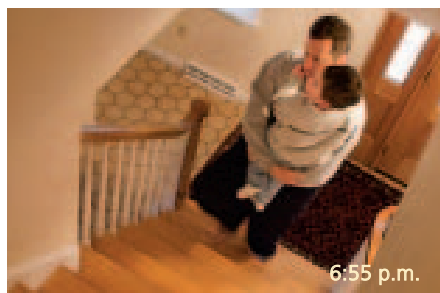
and pool (Jimmy loves the water more than anything). The house is bigger, too, and has more bedrooms. Enough, in fact, to tempt Michelle into thinking about—maybe—another baby.

**6:30 p.m.** Dad helps Jimmy stab the final noodle onto his fork. "Good eating, Jim," Michelle praises, as Jimmy takes his last bite. "Great job, Jim," echoes his father. It's a sure sign dinner is over, and Jimmy kicks his legs in anticipation of a spin on the computer. This new obsession grates on Jim: "He'd stay there all day if we let him." Jimmy chants "*Kuh, kuh, kuh, kuh.*" Jim sighs. "I know. Mommy told you you could."

"You deserve it," Michelle reassures Jimmy. "You work hard all day." To Jim she adds, a bit defensively, "He hasn't done it all day." ➤



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**6:35 p.m.** Jimmy slides out of his chair and makes a beeline for the downstairs guest room. The door is closed, and he struggles with the knob—one of many fine motor skills he still can't manage—until Jim helps him out. In a flash he's in front of the computer, his right hand clutching the mouse, head tilted back, blue eyes peering at the blank screen, vocalizing loudly: "Mmmmm, aaaaaah."

"Yeah, I know, you've got to wait a minute," Jim says as he switches on the hard drive. He lifts Jimmy into the chair as the screen lights up. In moments Jimmy has taken himself to the Sesame Street website. He may not be able to turn a doorknob, but he is quite deft with the mouse—thanks to desire, maybe, or to practice. Count Von Count's Transylvanian drawl welcomes him, followed by the sound of Maddie's little feet running from the kitchen. "I go the Counter too!" she squeals, taking up her usual tiptoe station to Jimmy's left.

She points to another character, and Jimmy obligingly clicks on it. "Me can only eat things that start with the letter T," Cookie Monster declares. Jimmy quickly clicks on the right items—a top, a tuba, and a tie. He has less luck with Elmo's rhyming game. Asked to pick an item that goes with "dog," Jimmy clicks on "moon."

**6:55 p.m.** Michelle appears in the doorway. "Jim-Jim, let's turn off the computer," she announces matter-of-factly. He wails loudly as she takes the mouse from his hand, but the protest is short-lived. These days Jimmy is pretty good about such routine transitions. The bigger ones, though, are still a bear.

One hallmark of autism is an obsession with predictable patterns; changes in routine can be deeply disturbing. The move to the new house so undid him that he acted like he couldn't walk the first few days. "Anytime I would leave the room, he would just start bawling," says Michelle. "He'd fall to the ground, and you'd pick him up and he'd just lie there. We had to carry him upstairs."

At their old house, Jimmy's low muscle tone and difficulty planning movements made him unsteady on the steep, narrow steps. The steps in this house are wider and Jimmy often climbs up, gripping the railing. A few weeks ago, though, Jim slipped while carrying him, and the two slid the length of the staircase. Jimmy was unhurt but so shaken that for days he was terrified of even the small block steps he climbs in physical therapy. Jim now tries to coax his son upstairs, but every-one is too tired and Jimmy ends up getting a lift. ►►



“I see Jimmy teasing Maddie more and laughing at her being silly,” Michelle says with pride. Any sibling playfulness feels like a miracle for the Foards.

**7:00 p.m.** Bath time. Michelle pulls off Jimmy’s clothes and peels off his diaper (dressing and toileting are two tasks he has yet to master), and it’s into the tub. Maddie too. For a while Jimmy pours water and plays with a kazoo, paying little attention to Maddie until he fills a huge red cup to the brim and dumps it on her head, drawing peals of laughter from both of them. “He got you!” exclaims Michelle, as Maddie cracks up. “He got you really good!” He pours another giant cupful over Maddie, then another. Soon her laughter gives way to whimpering, and Michelle reaches in to rescue her. The two frequently rile each other up.

And yet, even riled up, any sibling playfulness feels like a miracle for the Foards. Maddie has always been fascinated by Jimmy, imitating and praising him nonstop. Still, it’s been mainly a one-way relationship. Children with autism can need a lot of coaxing to engage with others, and Jimmy is no different. But that’s shifted lately. “I see him teasing her more and laughing at her being silly,” Michelle says with pride. “Sometimes they’ll hold hands.”

**7:20 p.m.** Down the hall, Maddie is bouncing on the white sleigh bed in her pink-walled room. “Look at me, everybody!” she declares. “I jumping!” To date, jumping is about all she’s done here. When the Foards first moved into the house, Maddie’s room wasn’t ready, so they put both kids in Jimmy’s big bed, and it’s been that way ever since.

Jimmy pads to his room, climbs into bed, and Michelle gives his teeth a once-over with an electric

toothbrush. Brushing in bed is the only way she can get the kids to open their mouths wide enough to reach all their teeth. “And then they drink the water, which I know is bad,” Michelle admits, “but I can only do so much.”

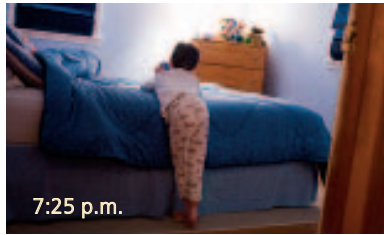
**7:30 p.m.** Everyone is on the bed. Michelle shares a book with Maddie as Jim, spooned around Jimmy, reads from *The Cat in the Hat*. Jimmy squeals delightedly, slaps the pages. He grabs his dad’s finger as it traces the pictures, placing it on items he wants identified: umbrella, fish, hat. Every time the page is turned, he stiffens his legs, feet angling for the sky. It’s his body language for excitement.

“The end,” Jim announces with relief. “That’s a long story. Let’s go to sleep.” But Maddie is climbing onto the bed with another book. “Oh,” says Jim, resignedly, “*Follow the Leader*.” A few weeks ago Jimmy took this one to preschool for show and tell. “This-is-my-favorite-book,” he told his classmates, using sentences Michelle programmed into his electronic speech device. “My-parents-read-it-to-me-at-bedtime. I-like-to-say-bye-bye-to-the-animals.”

The moment the second book ends, Maddie clamors for another. “No, we’re all done,” Michelle says quickly. “All done,” chimes Jim. “Lights out.” “Night-night, Daddy,” Maddie chirps as they lie in the dark. “Night-night, Bubba” (her pet name for her brother). “Bubba, give you a kiss,” Jim says, “Bubba’s sleeping. Okay, everybody go to sleep, please.” Silence for a moment, then Maddie’s little voice: “Night-night, Bubba. Goodnight, Bubba . . .”

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**7:45 p.m.** After 15 minutes Maddie is still Bubba-ing away. Jim takes her downstairs to keep her from waking Jimmy. She's had a cold, and daytime naps are wreaking havoc with her nighttime schedule. It just adds to an already difficult situation, one of the few areas of tension between Jim and Michelle. Ever since the move, the kids have been waking in the wee hours and climbing into their parents' bed. Jim is a light sleeper, and it's driving him nuts. Most nights he ends up fleeing to Jimmy's abandoned bed. He and Michelle keep making plans to break the habit, but something always gets in the way.

**8:00 p.m.** Michelle wanders into the kitchen, yawning. Though she often falls asleep with the kids, she managed to rouse herself tonight—just barely. She takes Maddie from Jim's arms and plops into a chair. It's been a long day. "This morning she woke me up at, like, four o'clock," Michelle says with a sigh.

These days, the Foards say, Maddie's usually the more challenging child. She is full of energy and "moody, like her mother," says Jim with a chuckle. "She's very hard-headed. She's 2." Her behavior is just one more reminder of how different their children are. Along with a host of other childhood milestones, Jimmy missed the contrary phase.

Yet even with Maddie's willfulness, the demands of the new house, and Jimmy's hectic school and therapy schedule, life feels more manageable. Maddie is walking and talking. Jimmy is expressing himself through his handheld speech device, gestures, and sounds. And Michelle is regaining a life of her own, going out with friends, taking an upholstery class, and volunteering for special-needs organizations. It's a far cry from two years ago, when the overwhelming pressure of coping with a

new baby and Jimmy's autism diagnosis brought on panic attacks and debilitating anxiety. Michelle still takes anti-anxiety medication—and her newfound sense of calm is one reason Jim is not eager to expand the family. "It's starting to get a little easier," he says. "Why upset the apple cart?"

Michelle carries Maddie into the den, where they sink down on the couch. At such moments of pure exhaustion, Michelle is convinced the idea of another child is crazy. Then she sees a pregnant friend or a cute infant, and the longings start again. Recently she started weaning herself from the anti-anxiety meds in preparation for pregnancy—the same week she renewed her birth control prescription. "I'm hot and cold all the time," Michelle says.

Jim's not sure he could stand another pregnancy, never mind the intense baby years. They suffered through months of anguish waiting for Maddie, after an early ultrasound showed possible signs of a brain disorder. "I just didn't sleep for the better part of the pregnancy," Jim recalls. When Maddie arrived she was fine, with a full head of dark hair that may have caused the troubling shadows. Having had Jimmy gives them only a 10 percent higher chance of having another child with disabilities. But the risks for the whole family loom large.

"It all goes back to Maddie," says Michelle. "We've talked about having another sibling just to have somebody else if Jimmy needs help down the road," explains Jim. A financial advisor, he already has set up a trust to support their son after he and Michelle are gone. But Jimmy will need much more than money. "Even thinking about placing that burden on Maddie . . . I can't place that burden on her," Jim says, his voice filled with angst. And the question of a third child remains unanswered. ●



Charlotte Meryman's award-winning newspaper series about an autistic child, "The Race to Reach Elijah," can be found on her website: [charlottemeryman.com](http://charlottemeryman.com).

**Next in the series:** The Foards deepen their connection to the special-needs community. To read earlier installments, visit [wondertime.com](http://wondertime.com).