What they don’t talk about: One family’s life with three children on the autism spectrum

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Elizabeth and George Tolis don’t often talk about what it’s like to raise three autistic children. But when the Jamison couple is asked to, they seem even surprised themselves how much they have to say. And they’re only saying it now because they’re asking for help, even though they don’t want to.

“It’s not in our nature to complain or say how hard it is,” offered Elizabeth.

The Tolis’ 7-year-old twins Damian and Zack were diagnosed on the autism spectrum when they were in preschool. Their youngest son, 5-year-old Emmett, was diagnosed just after them. Three years with three consecutive diagnoses.

“Today, they say one out of 66 boys have autism. I have three of them,” said Elizabeth.

Emmett is the most severe, nonverbal and intellectually disabled. “His mentality is that of a 2-year-old,” noted George. But, at five years old, that mentality means he’s a danger to himself and his family.

For a while, Emmett liked to jump off his furniture. Recently, George came home from work and looked up to see his son standing on the windowsill of the third-floor room. Now the only furniture in his room is a bed and low dresser. Soon, there will be bars on his windows. In the living room just below his room, nails are coming through the ceiling.

There’s a water stain on the ceiling in the dining room. One night, George and Elizabeth woke up to splashing. Emmett was in an overflowing tub with a blow dryer and hair curler, both unplugged. Now they lock his bedroom door every night.

Due to sensory issues, Emmett refuses to eat anything that’s not bite-sized, crunchy, white or beige, and just the right consistency and temperature. He hasn’t taken food from a fork or spoon since infancy, barely drinks water and literally has never eaten a green vegetable in his life. At 5 years old, he’s anemic with chronic gastrointestinal problems and is on the verge of developing diabetes.

So the Tolises are risking what little financial security they have on a six-week food intervention program at Children’s Hospital of Philadelphia (CHOP). If it works, Emmett will allow himself to eat a much wider and more nutritious range of foods.

The treatment is covered by insurance, but Elizabeth will have to drive him there five days a week. When that’s done, she’ll continue what he’s learned at home, navigating his subtle, non-verbal cues to decipher what’s working or not. There’s an eight- to 12-month follow-through period, and she’ll have to transfer those skills to her husband.

That means paying someone else to run her business, Center Stage Dance Studio in Hatboro, for months. Since she’s the owner, whoever replaces her will need a larger salary than what she draws for herself. The twins will need a babysitter, but one who’s properly trained is more expensive.

“You can’t have the girl next door watch them,” said George. “They’ll eat her alive.”

It all adds up, and quickly. Elizabeth realized that the family, who often lives week-to-week, wouldn't be able to afford the extra care and income loss. But, that doesn't make soliciting support any easier.

"You don't want to ask for yourself," said George, the father in a family that's raised upwards of $30,000 for groups like Autism Speaks.

The Tolises regularly held events like support nights at the Chick-Fil-A. Once, they raised $1,000 in four hours, more than the school groups that usually hold these events. But, after three diagnoses in three years, there wasn't time anymore for fundraising events.

Now, they're trying out Support Local Stuff, a crowdfunding website that focuses on small, local campaigns for anything from pee wee football uniforms to medical issues. It's a site where people can read about a cause and donate any amount they wish.

The Tolis' goal is to raise $6,000 by Sept. 23 just to cover those extra expenses so Emmett will eat something — anything — with nutritional value. But large-scale charity efforts were different than asking for their own, personal donations.

It's an easy way to get a little from a lot of people, rather than try to pull from the same ones who've donated in the past. Already the Tolises are seeing pledges from strangers, and considers every post about it on social media sites as an opportunity to raise awareness.

Still, said George, "It was easier to raise money for big groups than to say it was for us." And it's especially awkward for a family in Jamison.

"It's the perception. People see where we live and think, 'Why am I gonna donate to that guy?'" he continued. "Across the street are $800,000 houses, and down the road are $2 million houses."

But the Tolises bought a house in the less expensive part of Jamison, before any of their children were diagnosed. Though they struggle to pay their bills, Elizabeth insisted that moving into the house was the best thing that's happened to them.

"There would be no other school district in the area, maybe with the exception of Council Rock, that would be able to take on the needs of the children to the capacity that Central Bucks could," said Elizabeth.

It's a true story, but it's long and a little confusing. So they don't talk about it. In fact, they don't get to talk about a lot of things.

The Tolises are a married couple in a situation that produces a high divorce rate, anywhere from 50 to 80 percent, depending on the study. They're parents who, on many days, see each other just long enough to literally high-five each other as George gets home from work and Elizabeth heads out.

George estimated he's gained nearly 60 pounds over the last five years from "eating the same junk" the kids often consume. He's lost many friends because he doesn't have time for them, and no longer identifies with his buddies, even the ones with kids.

Elizabeth is a torrent of scheduling and tasks like monitoring Individualized Education Programs (IEPs)and service plans for each child, following up on doctor's appointments and lining up counselors for in-home guided care. Before the kids were in school, she managed 40 hours of therapy over 18 therapists every week.

Recently, she fought for a private van versus a regular yellow bus to transport Emmett to school in Lansdale. But that victory brought the ongoing anxiety of putting a 5-year-old kid with no ability to express himself with a stranger on a bus for an hour-long ride.

Emmett goes to school with other developmentally disabled kids, and occasionally there aren't people on staff. He started coming home with black eyes, bruises and scratches, and due to privacy laws the teachers weren't allowed to tell the Tolises which kids were responsible. Elizabeth used the school's open-door policy for a week to observe the classroom and point out to the the staff who needed more attention.

But usually they don't talk about it.

Elizabeth learned long ago not to get into it because she'd end up talking only about learning the cues to tell if her preschooler has a dirty diaper, or how he'd regressed to always curling up his hands into fists.
"I choose not to dwell on all the difficult things," she said.

George rarely sees parents any more. He can't take the frustration, he said of hearing his mother insist that he did the same thing when he was Emmett's age and that Emmett would just grow out of it.

"Like, really? I didn't talk when I was 5?" said George.

But he understands the sentiment: "The word autism didn't really exist when I was in school. I graduated in the '80s, we had the weird kids, the special ed kids, the retarded kids."

But mostly, they didn't talk about it.

Many times he and his wife can't even talk to health professionals about it. Any emergency room visit — and there are plenty of them — requires a trip to CHOP in Philadelphia. The one specialist on hand in most hospitals doesn't catch the nuances of a kid who can't just hold his stomach to at least indicate a gastrointestinal problem.

Once, George told an ER doctor his son was non-verbal. The doctor assured him that, under enough stress, he'd say what was wrong. "So that's it!" said George when he recalled the conversation. "That's it! We just cured autism. Just stress them out enough."

He raised his voice only slightly. He discussed the challenges of raising three children on the autism spectrum with the same mild frustration the average dad expounds talking about a teenager who doesn't clean his room and plays loud music.

And, he waited until Elizabeth wasn't around to talk about the friction between them when he resisted the idea that there was something wrong with his Emmett. Finally, the family was at a company outing, and instead of playing with the other kids, Emmett was off on his own, just sort of swaying.

The Tolises left the event early. Soon after, Emmett was diagnosed. George and Elizabeth's relationship improved, but the hard work began. Again. Three years, three diagnoses.

George goes to work and watches the kids at night. No hobbies, no nights out. He wouldn't be able to leave the house if he wanted to until 11 p.m. Then he'd just need to be up again the next morning, and his wife's such a heavy sleeper he wouldn't relax.

Elizabeth at least has Center Stage. The studio's homepage quickly mentions how the accomplished singer, model and actress was once on the cover of Newsweek. She doesn't talk about it. The studio is a labor of love, she said, one that barely yields a paycheck but helps her "mentally rejuvenate" each day. What does George do to unwind?

“Drugs,” he said, absolutely facetiously.

Actually, he high-fives his wife as they pass like ships in the night.

And they don’t talk about it.

Emmett doesn’t talk about it, either. He doesn’t talk about anything. When he comes downstairs, you hear him through tinny speakers before you see him. He’s the youngest kid in a house that still has intercoms, baby gates in the doorways and plastic child safety bubbles on the door knobs.

He runs up and grabs George’s phone. It took him hours of rote training to use a simple app that helps him identify everyday objects. Later, he moves onto lining up toy cars.

“He doesn’t play with them like cars. he doesn’t say, ‘vroom vroom,’” said Elizabeth.

Soon, there’s a design where 40 or so toy cars in a line snake around the furniture. “This isn’t one of his more complex ones,” she noted.

But it’s not as simple as that. The line diverges in spots. The procession suddenly loops or turns regardless of the contours of the space available. It’s like looking at crop circles, or hieroglyphics from an ancient language to which there’s no key. There’s almost an energy emanating from the design.

And that, Elizabeth said, is part of what makes him special. “There’s something special and unique about Emmett. I’m sure I’m biased, but he just affects everyone he meets. I don’t know how he does it.”

But that abstract sense of expression is often all they get. That or a bright, genuine smile in one out of every 75 pictures the family takes of him – the one picture out of nearly 100 they show people.

But his family doesn’t talk about it. And Emmett doesn’t talk about his family.

Actually he did, once. Sunday is the only time when all five Tolises are all together. One Sunday, after months of work, Emmett managed to touch each family member’s upper arm with the backside of his hand and approximate their names verbally.

“We were in tears, it was such a big deal,” said George. Elizabeth compared her son’s accomplishment to “climbing Mount Everest.”

But Emmett regresses constantly. “The only thing that’s consistent about Emmett is that he’s not consistent,” said Elizabeth. She and George learned to appreciate the little things when they happen and not to expect them to happen again.

Professionals use rewards to help children with autism do things like identifying everyday items on flash cards. “Kind of how you’d train a dog,” Elizabeth ruefully admitted. They often use food, but she refuses that because of Emmett’s food issues.

So they have to figure out what his “thing” is at the time. For a while, it’s been traffic signs, and when he starts his food intervention they’ll let him hold a traffic sign if he eats what they put on the table for him.

People would say to just put the food in front of him. Eventually, he’ll get so hungry he’ll eat. One of the times Emmett went to the hospital, he hadn’t eaten for 36 hours.

So the Tolises will risk unpaid bills and longer hours just so someday soon their 5-year-old won't require an IV for basic nutrition every so often. Elizabeth hopes that his cognitive skills will improve, too, with better more consistent nutrition.

But that's an ancillary goal. If he just eats anything other than crunchy, white-to-beige-colored food that's just the right temperature, Elizabeth and George will feel like they and their son just climbed Mount Everest.

For Damian and Zack, the Tolises have goals for them to one day live independently, manage finances and have relationships. Emmett, will always live with them. That's all they can project right now.

"I'm happy when he puts his shoes on. I'm happy when he gets dressed by himself. I'm happy when he takes his diaper off and pees on the floor, because I know he understands that that sensation happened and he was going to pee," said Elizabeth. She looked, just for a moment, as if she'd briefly seen the forest through the trees.

George and Elizabeth will always work, and always care, for him, every day. For now, they try every so often to carve out some time for themselves when they're not talking about the kids or IEPs or the latest counselor who just "disappeared" because organizing care for one child on the spectrum is hard enough but with three it's nearly impossible. All so they won't become part of the many married couples with autism spectrum children who get divorced.

For moments like when Emmett taps them on the upper arm with the back of his hand and makes sounds that are almost their names.

For the moments, too, when they're sitting on the couch talking about what's on the screen of the cell phone Emmett's holding. When he still seems oblivious to his parents — both of them, despite the high divorce rates — beaming radiant smiles at him.

But for now, it's time for George to return to work. As he left, the twins crashed through the room.

Nearby, Emmett burst into tears. No one knows why. He doesn't talk about it.

Elizabeth tended to the crying 5-year-old who can't tell her what's wrong. George will be back in a few hours for his shift, when he'll pass his wife on her way out. Maybe they'll high-five.

She picked up Emmett. George left silently.

They don't talk about it.

For information on Emmett and his crowdfunding campaign, visit http://www.supportlocalstuff.com/oursweetboy.