THE REST OF YOUR LIFE

Raising a Child With Special Needs

It's been 10 years since Elyse May was born with congenital adrenal hyperplasia, but her mother, Michelle May, M.D., remembers the experience as if it were yesterday.

While Dr. May suspected that her daughter had congenital adrenal hyperplasia, adrenal disorders "are not my area of specialty, so my husband ran to the medical library for books that might help," recalled Dr. May, a family physician who practices in Phoenix, Ariz. "There I was, having given birth about 12 hours before and reading medical textbooks in my hospital bed."

Once the diagnosis was confirmed, Dr. May and Elyse were discharged home without starting treatment. The endocrinologist told her it was unclear whether Elyse had the mild form of the disease or the severe form. "He said that if we started to treat the mild form, it would mask the severe form," Dr. May said. Then the endocrinologist went out of town.

Once home, Elyse began vomiting and she became jaundiced and dehydrated. "By the time they decided to start her on the steroids, she was so sick that we put her in the hospital for 3 days," said Dr. May.

"We really did almost lose her. It was very scary to be a patient in that situation. I couldn't get anyone to listen to me about how sick she was until I finally begged them to let me take her into the hospital. The doctor there said that she probably could have died within 12 hours."

Today, Elyse manages her condition by taking oral steroids three times daily. She wears a MedicAlert bracelet that attracts interest from her peers at school.

"Kids are starting to ask, 'Why do you wear that?' " Dr. May said. "She doesn't want to stand out. She doesn't want to be different. Because of the nature of her condition, if she goes to a sleepover or a birthday party, I have to let parents and other caretakers know about the potential seriousness if she does become ill or injured. I tell them you have to make a double effort to notify us if something happens because she could die of this if she's not treated appropriately."

While the prognosis is excellent for Elyse "as long as she never has an adrenal crisis that is mismanaged, we still have to make sure we do the follow-up appointments and the routine blood work," Dr. May said. "I am now more empathetic to patients who have chronic medical conditions that require a lot of attention. It's easy to get into a role of complacency, or you get busy and you don't do what you should right on time."

Mark Heinz-Graham has a different set of special needs. Born with a moderate range of intellectual functioning, the 27-year-old currently reads at the pre–first grade level, "although he's very motivated to learn how to read," said his mother, Lee Combrinck-Graham, M.D., a psychiatrist who practices in Fairfield County, Conn. "In fact, he has just started with a reading teacher who hopes that now that he is an adult, there are more strategies for helping him to learn. Numbers are elusive [to Mark]. Math is not in his repertoire."

She noted that Mark relishes his full-time job as a grocery store bagger. He also likes to watch TV, play computer games, swim, play the drums, and listen to opera. "He's also in an art class," she said. "He's learning to be more deliberate, careful, and thoughtful."

She said the most difficult part about having a child with special needs is observing the social isolation that occurs. "For example, they can go to a birthday party with regular kids or with special-needs kids. But somehow their participation in it or their 'getting it' is at a different level, so they're sort of on the fringes," Dr. Combrinck-Graham explained.

"If you have a birthday party with six special-needs 6-year-olds, they're all into their own thing. So it's not really a social occasion except they're there and the parents are whooping it up.

"So what does Mark do on Saturday afternoons or Friday nights? That is a really important issue. To some extent he has a much more active social life than many special-needs kids, but it's not anywhere like what a 27-year-old's social life could be."

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That's not to say family members don't include him in their regular social activities. They do. In fact, she said, "when our group of friends invites us for dinner, they usually invite him, too. Most of our friends like him and make an effort to include him. They understand that if he comes to dinner, there's going to be a part of the evening in which he's not going to be interested, and he'll go off and watch television."

She added that families of special-needs children "shouldn't feel ashamed or try to hide their kid and shouldn't feel reluctant to invite people in to help.

For instance, Mark is fairly independent. Sometimes we go away overnight and might say to one of our friends, 'Would you give him a call and say hi and see if he's alright?' Or sometimes when we go away someone will stay with him in the house. We do this so he has a larger circle of people paying attention to him while we're away. I've met some parents [of special-needs children] who say, 'Nobody would want to do that for my child.' That's not true. People really do want to know what to do, so they need to be included with your friends and family. Raising this child, loving this child, and making this child feel welcome is a collective activity. None of the tasks should be assigned to just one person."

Dr. Combrinck-Graham noted that it took a while for her own mother to accept Mark as he became an adult. "She likes to have intellectual conversations and she constantly displayed disappointment [in him], which I don't even think she was aware of," she said. "I finally said to her, 'He's not what you wanted him to be, but he is who he is. You're missing out on a great opportunity, so why don't you get over it?' Now, most of the time she's really getting a kick out of him."

Elisa Nicholas, M.D., reiterated the importance of focusing on the assets of a child with special needs. But she pointed out that the competitive, achievement-focused culture of medicine can pose a challenge to that effort.

"If you sit around a doctor's dining room and everybody's talking about their over-achieving child, and you're simply trying to get your child to walk and talk, it is very difficult," said Dr. Nicholas, whose 16-year-old son, Tom, has cerebellar ataxia. He copes with difficulty walking, general coordination problems, and cognitive challenges.

Tom—the first physically challenged student to be fully integrated into the Hermosa Beach (Calif.) School District—wears braces on his feet and uses a walker, crutches, or a wheelchair for mobility. "He can dress himself, but he will never be able to put his braces on by himself," said Dr. Nicholas, a pediatrician who directs The Children's Clinic, Serving Children and Their Families, a system of six not-for-profit community health centers in Long Beach, Calif. "He's always going to need some assistance."

When Tom was diagnosed with the condition at age 16 months, "we were all depressed and frightened in not knowing what the future might hold," she said. "It's difficult because I think most physicians to some extent are able to control their destiny, [the idea that] if you work hard enough you can achieve something. But in these kinds of situations, you're not in control."

She also knows the caregiver role consumes many parents.

"I think trying to achieve a balance is truly a great challenge," she said. "I want Tom to reach his greatest potential. If that means I have to make personal sacrifices, I will do that. But it's very difficult to find that balance, because it can become all-consuming. While it can become all-consuming, it is imperative to take time for yourself, your spouse, and your other children." ■

By Doug Brunk, San Diego Bureau

COURTESY DR. MICHELLE MAY

Dr. Michelle May says that her daughter Elyse's congenital adrenal hyperplasia has made her more empathetic to patients with attention-consuming chronic health conditions.