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Palm Beach Coast girl suffers from selective mutism

By Carolyn Susman, Palm Beach Post Staff Writer

Tuesday, April 20, 2004

From the beginning, Christine was different.

As an infant, she hated being held, arching her back when anyone tried to pick her up.

She wouldn't sit in a car seat or a high chair, wriggling, squirming and screaming to get out.

As she grew, she would run and hide under the bed when company came to the house; she walked on her knees because she didn't seem able to tolerate the feel of carpet on her feet.

If her parents tried to take her anywhere to visit, she would scream and throw herself around.

Doctors thought she was autistic, like her older brother Michael, or merely imitating him for attention. But her mother knew something else was wrong.

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Through the inconclusive diagnoses of autism, attention deficit hyperactivity disorder, obsessive-compulsive disorder and that old favorite, an "out-of-control child," Sharon Stangarone of Port St. Lucie held out hope that what was bedeviling Christine would finally be found. She held out hope, even when her daughter screamed so intensely at a psychiatrist's office one day that she passed out.

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But it wasn't until Christine, now 9, started attending St. Lucie County public school that matters started coming into focus.

"The kindergarten teacher said, 'Christine won't speak to us,' " Stangarone recalls. "It was a good six months till they got all their testing done."

Eventually, because Christine's symptoms didn't fit neatly anywhere, Stangarone and Christine's speech pathologist, Janelle McCandless, began surfing the Internet and discussing the child with other speech specialists.

The diagnosis of selective mutism, a form of anxiety disorder, popped up. And stuck.

The biggest giveaway? Christine's inability to speak in certain social settings, such as school, was accompanied by an ability to talk normally in other situations. You can't shut her up at home, for example.

But even in her home setting, and with those she is closest to, she will clam up if someone not on her "list" appears. She speaks only to her mother, father, brother and grandmother and a friend of her own age next door.

When she and her mother spent days at her grandparents' home, helping out when her granddad was ill, Christine never spoke to him.

And in three years, she has never spoken to McCandless, her speech therapist.

"It's a very sad disorder," says Stangarone. "It's really hard for people to be her friend. They always want her to talk."

But she won't talk.

People with selective mutism have such an overwhelming fear of speaking and social interactions that they often won't let anything out of their mouths. McCandless is encouraging Christine to make quacking noises as a way to communicate -- any method to allow her to verbalize in public.

"The key is what are these children like at home? Active? Most are," says Dr. Elisa Shipon-Blum, executive medical director of the Selective Mutism Group Childhood Anxiety Network in Pennsylvania (www.selective-mutism.org).

Changing a child's brain

Shipon-Blum claims to be the only doctor in the world to treat these children exclusively, and she got there the hard way: Her daughter had the condition.

But the child has now mostly overcome it. Shipon-Blum says, thanks to the use of

antidepressants for about nine months and a program of therapy that her mother devised.

"You change a child's brain. They don't have years of ingrained behavior. It sounds so funny, 'We change brains,' but we do, although Sophia is still shy by nature," she says.

The 9-year-old will now talk to a stranger on the phone -- a big leap. Asked why she didn't talk before, she says, "I felt scared." When asked about how she's doing now, she says, "When I was in preschool, my mom put me on medicine and I started to talk. I felt happy."

That's the goal for the estimated seven children in a thousand who develop selective mutism, a disorder more common than autism and juvenile diabetes, but which most people have never heard of.

Children who have this mental illness likely have a genetic predisposition to anxiety -- it's in the family -- and may behave as Christine did, with frequent tantrums and crying, moodiness, inflexibility, sleep problems, parental separation issues and extreme shyness, from infancy on.

"People don't understand the suffering these children go through," Shipon-Blum says.

"It's like taking someone who's afraid of heights and putting them on top of a 100-floor condo every day of their life," Stangarone explains.

There is no evidence that selective mutism is related to abuse, neglect or trauma. Without treatment, however, most of these children do not outgrow the condition.

Dealing with them is tiring and often seems fruitless.

Jennifer Wild, Christine's occupational therapist, addresses secondary effects of her condition -- poor handwriting, weak upper body and hand strength, poor eye-hand coordination.

Her attitude seems good when she goes for sessions, Wild says.

"She usually comes to therapy with a smile on, skipping."

But she is always silent, communicating through picture cards, gesturing and "making little vocalization sounds to get your attention."

In the private school she now attends, Christine will stand in front of the class to present projects, but she never talks. For her science display, comparing flowers in fresh water and salt water, she and her mom collected lots of photos and "had enough pictures so she didn't need to speak."

For another project on Italy, Christine did all the research, presented it to her speech therapist, McCandless, and McCandless recorded the report on tape. Then Christine stood in front of her class and "pushed play." McCandless did the recording, because Christine cannot listen to her own voice without "going berserk."

Child comes with warning

Because Christine's refusal to speak can often be misinterpreted as defiance, or lack of respect, she carries a card that explains her condition:

My child is a loving and intelligent individual! However, in social situations, my child often becomes mute and cannot utter a sound.

WHY DOESN'T THIS CHILD TALK ?

My child has an anxiety disorder called Selective Mutism.

My child often has difficulty smiling and making eye contact with people. This is not because my child is unhappy, purposely ignoring you, or trying to get attention. It is not due to willfulness, stubbornness or manipulation. It is because of anxiety and fear that can literally make it impossible to speak.

Although Christine is a chatterbox at home and appears to be an average child in some ways, Stangarone has a painful, daily reminder that her child is different.

"Till this day, every day, she tells me it feels like the first day of school every day when she has to go. She says her stomach hurts, and she starts crying. She's so scared to go back to school.

"The anxiety getting her there is almost enough to not even bother, but that wouldn't help her get better."

carolyn_susman@pbpost.com

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