

THE PENNSYLVANIA STATE UNIVERSITY  
SCHREYER HONORS COLLEGE

DEPARTMENT OF ENGLISH

WORDLESS: LIVING WITH SELECTIVE MUTISM

HELEN TANG  
SPRING 2017

A thesis  
submitted in partial fulfillment  
of the requirements  
for a baccalaureate degree  
in English  
with honors in English

Reviewed and approved\* by the following:

Elizabeth Kadetsky  
Assistant Professor of English  
Thesis Supervisor

Marcy North  
Associate Professor of English  
Honors Adviser

**\* Signatures are on file in the Schreyer Honors College.**

## **ABSTRACT**

This thesis is an autobiographical account of my personal experiences with selective mutism, an anxiety disorder that renders people afraid to speak in social situations. Although the condition can have severe negative impacts on a person's life, there is very limited research and awareness of it. This means individuals who have selective mutism are often undiagnosed, untreated, misunderstood, and mistreated. Through interviews with my family, research, and examination of other peoples' experiences, I have created a narrative that I hope will educate readers on the struggles people with selective mutism face. More importantly, I hope this thesis can shed some light on what can be done to treat and help improve life for those with selective mutism.

**TABLE OF CONTENTS**

Chapter 1 The Self Portrait.....	1
Chapter 2 The Beginning.....	9
Chapter 3 Mrs. Buck.....	18
Chapter 4 Problem Child.....	27
Chapter 5 The Intelligence Test.....	37
Chapter 6 Hidden Feelings.....	48
Chapter 7 Survivor.....	53
Bibliography.....	58

## Chapter 1

### The Self Portrait

*“Why is there no help available for children like Tom? Why isn't he deemed important enough? Why does no one take SM seriously? Why do the 'professionals' he has encountered have no understanding of SM? It's so wrong. It destroys our children's lives.” - Dawn, Selective Mutism in Our Own Words*

I sighed when Mr. Koons revealed what our next AP Studio Art assignment was. In order to show the great and mighty College Board that we were worthy, we had to create a self-portrait, one of my least favorite things to draw. It wasn't that I was bad at drawing. Art had been a hobby of mine since childhood, and with fourteen years of practice under my belt, I secretly thought I was more skilled than most of my classmates, whose works wouldn't have enough contrast between lights and darks, or wouldn't resemble the objects they were sketching at all. But although I had learned the techniques that made art look beautiful, I had not yet learned to think of my rounded, distinctly Asian face as beautiful. I never thought I looked good in self-portraits or photographs. In the former, there would always be something I drew a little off, a miscalculated proportion that made my nose too long, or a misshaped curve that made my face too chubby. In the latter, I'd notice the awkward asymmetry of my eyes, the right with double lids and the left without.

Still, I wasn't about to be a difficult student. I would do the assignment. I just had to figure out what exactly I wanted to make. After mulling over it for a while from my chair in the

classroom, I rose and took a little walk to see if my classmates could inspire me. Peeking over their shoulders, I noticed lots of them were simply replicating previously taken photos of themselves and adding a bit of flair. One girl was looking at a shot of herself in a plain bedroom, but her illustration showed her bathed in the light of a stained glass window, her skin tinted an ethereal blue. Another girl was etching flower tattoos on her portrait's cheek, the petals blood red with thorny vines radiating out from them. No matter how well or poorly they were drawn, each addition seemed to say something about what the artist was like as a person. Girl One came off as serene and mysterious; Girl Two was a budding femme fatale.

I sat back down in my seat. I decided that I, too, would use the self-portrait to show what I was like, but which side of me did I want to display? As I thought, I opened up my school binder, and my eyes landed on the notepad stashed behind a mesh at its front. It was a well-used little thing, five by eight inches, with lined paper that was starting to wear around the edges and pages completely scrawled over on both sides. As beat up as it was, the notepad was precious. It was my Braille, my sign language, my communicative lifeline. Without it I would have no way to convey my thoughts to the vast majority of people at the school.

*Bingo!* I took the notepad out of the binder. I now knew what I wanted to draw. And because the notepad was so important, I was one hundred percent ready to rip its pages apart to appease the AP Art gods.

I guess I should clarify. What was important was having a notepad on me, and not that particular notepad itself. I had plenty of replacements back at home, so I could afford to sacrifice it; I would've had to toss it anyway since it almost had no more writing room. Its contents were pretty boring too. It was mostly answers to questions for my AP U.S. History Class, such as “what was the Louisiana Purchase?”. Better to make art than make trash, right?

I started tearing the pages into small pieces, their sentences becoming inscrutable fragments of half-words and phrases: “China”, “so why is it”, “do you”, “food.” The work was repetitive, yet enjoyable in a mind numbing sort of way, the calm state I imagine people achieve through meditation, except I apparently achieved it by destroying the heck out of paper. Within a few minutes, I had a pile of scraps on my table, enough to fill the background of my future drawing. Now it was time to take a photo.

There was a small room off to the side of the three main art classrooms, which I never really understood the purpose of, as I very rarely saw people inside. I think it was mostly used for storing supplies and artwork, but a round table in the corner implied that perhaps students could use it as a work space. In any case, the teachers had temporarily turned it into a photography room. There was a camera on a tripod along with a white backdrop and two lamps for lighting. I walked inside with a roll of masking tape and my fellow artist and friend, Lucy, who would take my photo.

I stood before the backdrop and ripped off two segments of tape, sticking them over my lips in the shape of an X. I was also wearing my light blue scarf, which I contemplated taking off, but left on since I enjoyed the challenge of drawing folds. In retrospect, the scarf added to the symbolism that was starting to build up in my head, an accomplice of the tape sealing my mouth shut. We angled the lamps so there would be a balance of light and shadow on my features. Lucy aimed the camera at my head and hit the shutter.

We returned to the art rooms and I printed out the photo in black and white. I grabbed a large piece of paper and started sketching the contours of my face as they appeared in the picture. Starting a new drawing is always a nice feeling; I'll fall into this deep trance where all I can think about is rendering the image as accurately as possible. *Put down this line. Then this one.*

*Compare the distances, compare the angles. Does that look wrong? Erase it and redo it. Now the proportions seem right. It's time to start filling in the figure with textures and shadows.*

The process took several grueling days of intense focus, as well as several inches of pencil, but eventually, the image of myself came to life on the paper. After I laid down the last bit of graphite, I took my notebook scraps, which I had saved in a Ziploc bag, and glued them down around my form. Once the rubber cement dried, I picked up my self-portrait and held it at arm's length to view of it in its entirety. I grinned and felt the warmth of satisfaction come over me. It was complete.

Or at least, the art portion of the project was. We were also required to type a short message about the creation and purpose of each piece, which would be displayed alongside its respective art at our upcoming senior art show. Normally I might have struggled with this; I usual draw just for the sake of making something pretty, and not because I want to convey a certain idea. But this time was different. I felt a strong need to finally make a statement about a problem I had for most of my life. This urge was probably spurred by the fact that graduation was just around the corner; I did not want to leave high school without letting people know about this part of me.

~\*~

The book *Selective Mutism in Our Own Words* defines selective mutism as “a situational anxiety disorder of communication.” When a person has this disorder, they become “phobic of initiating speech/being overheard in the proximity of a given trigger person or collection of people”, and “may be able to speak in one situation...but be unable to speak...in another.” To put it more simply, selective mutism (or SM) is an uncontrollable fear of speaking in certain circumstances or to certain people. It is a fear that I have lived with for fifteen years.

Selective mutism begins during childhood and is believed to have a fairly high incidence rate, occurring in roughly 1 out of every 150 children, as well as in 1 out of every 2,400 young adults.<sup>1</sup> This is almost as frequent as Autism Spectrum Disorder's incidence rate of 1 in 68 children,<sup>2</sup> yet very few people know of selective mutism's existence or understand it correctly, even among doctors and psychologists. Because of this lack of awareness and underreporting, the numbers may actually be even higher. To put into perspective how little known SM is, here is some information I gathered while researching the condition:

- If you look up selective mutism on Google, you only get 439,000 results, while looking up “autism” nets 89,300,000.
- Likewise, looking up selective mutism on my university's library site only gave me 11,861 results.
- There is very little proper research on SM. As the woman who treated me wrote, “most research results are based on subjective findings of limited children,” with virtually “no long-term follow-up studies” conducted to examine the effects of appropriate therapy.<sup>3</sup> This leads to texts having either blatantly wrong or absolutely no information on the condition. I saw this for myself when I read in a psychology journal that children “*select* the people to whom they will or will not speak,” have a “conscious determination not to speak,” and use their silence “to exclude others.”<sup>4</sup>
- There aren't many books written by people who had selective mutism. In fact, it was only in 2016 that *Selective Mutism in Our Own Words* was published.
- The only well-known example of selective mutism in mainstream media is Raj from *The*

---

1 Sutton and Forrester 15

2 “Autism Spectrum Disorder”

3 “When the Words Just Won't Come Out”

4 Omdal 237, 238, 243

*Big Bang Theory*, and his SM is used as a comedy device.

- A number of people thought SM was a made up condition until they realized it fit perfectly with the strange silence of someone they knew.

Lack of knowledge is a problem. Without awareness and understanding, children who have SM cannot be diagnosed or receive proper help. They often suffer, misunderstood by those around them, and may get mocked and punished for failing to speak. Their mutism, far from being something they can grow out of, can last far into their teenage years and even adulthood if left untreated. In worst case scenarios, it can lead to dropping out of school, depression, other anxiety disorders, and an inability to live independently.

My self-portrait, titled “Muted,” was an attempt to raise awareness for selective mutism. When the day of the art show came, hundreds of visitors from both within the high school and out flocked to view my class's work, and my section was right by the show's entrance, one of the first things people would see when they walked in. “Muted” seemed quite noticeable; graphite Helen's black form contrasted sharply against the white foam board she was pinned onto, and her dark gaze watched everyone with the motionless intensity that only a picture could have. As I wandered around the area, chatting with friends and admiring other students' artwork, I snuck glances at my own section to see if people were stopping in front of my self-portrait. Every time someone did, a warm little spark lit up in my chest. I hoped they would remember its message.

~\*~

I graduated from high school in 2013 and began my life as an English major at Penn State University, where no one knew I had SM. For the first time since first grade, I could speak in public with absolute freedom. I raised my hand in class and answered questions aloud. I formed friendships by having conversations. At restaurants, I could order food by speaking instead of

pointing to the menu. I even tutored symbolic logic and spent my sessions talking in front of anywhere from one to fifteen people. What had once been impossible was now so normal that I barely thought about all the effort it had taken to battle SM, nor did I even feel particularly triumphant. The Helen who had selective mutism was transforming into a stranger, a completely separate entity from myself.

But perhaps because she was growing distant, I became more curious about her. During those times where I had nothing better to do—when I was lying in bed trying to sleep, taking a hot shower, or going on a walk to stretch my legs—I'd think about my past. How had I stopped talking in the first place? How did I feel about my struggles now that I could look back on them with more knowledge? How would life be different if I never had SM?

I also began to wonder what life was like for other people with SM, how similar or different my experiences were compared to theirs. If it weren't for the miracle known as the internet, I'm not sure I would have ever learned anything about my fellows. In all my life, I have never met another person with selective mutism in-person; I was the only child in my school district who had it, and I'd never heard of any SM support groups around my home. But through the internet, I found books, journal articles, and websites that discussed selective mutism—even if they numbered few.

After reading through it all, I felt lucky, but I wish I didn't. Many individuals had much worse experiences than I did. A woman named Alison “was never diagnosed nor received any treatment for SM,” and her anxiety reached the point where she “dropped out of school at the age of 16” and now struggles to find employment as an adult. Another woman named Danielle began having panic attacks at age 12 as a result of her SM, sometimes having “up to 60 panic attacks a night...for nearly three years,” and subsequently had to repeat a year of school. Kimberly, in her

desperation, thought getting drunk would help her talk and nearly died of alcohol poisoning at age 13. Vivienne, instead of receiving help at school, was forced to undergo a pointless medical “examination” where she was ordered to undress for no apparent reason and then sent to a nurse who “demanded to know why [she] had not attended...the local child guidance clinic”; upon visiting said clinic, she was taken to a psychologist who she could barely speak to, and he took her silence personally, accusing her of not trusting him.<sup>5</sup>

There are so many other stories—too many—but those were some of the ones I found particularly heartbreaking. My personal experience has taught me that life does not have to be so miserable for people with SM, but unless you are blessed with family, friends, teachers, and therapists who are knowledgeable on the condition or at the very least patient and willing to assist, happiness and success can seem unobtainable. Although we are slowly gaining more understanding of SM, it is clear that we can be doing a lot more. The predominant concern throughout all of my reading is that due to ignorance about SM, there are no support systems for those who have it and very little clue of what can be done to help.

Perhaps my case was not the most extreme, but because I was successfully treated, I feel a duty to speak up about how my own SM was handled. I hope that I can contribute some new insight into the nature of SM, its impact on life, and most importantly, how it can be defeated. And while I can't speak for everyone's personal experience, I'm sure there are many children and adults out there who feel the same way I did when I was younger—scared, alienated, and helpless, not even able to explain their predicament with words. For these people, I write. For these people, my self-portrait hangs on the wall.

---

5 These personal accounts and more can be found in Sutton and Forrester's *Selective Mutism in Our Own Words*.

## Chapter 2

### The Beginning

*“Very often the onset of SM is inexplicable and/or the trigger is small (at least from an adult point of view).” - Carl Sutton, Selective Mutism in Our Own Words*

We cannot talk about selective mutism, I believe, without first talking about how it might come into existence. Since my own SM developed during my early childhood, a time I barely remember, I consulted my parents to help me construct the narrative of this section by putting together our memories. As a result, the story presented here might not be exact. Still, it lays out the general sequence of events leading up to the emergence of my SM.

When I was a toddler, I lived with my mother, father, and maternal grandparents in the suburbs of Philadelphia. My parents had immigrated to the United States from China, and after my birth, my grandparents came over too, in order to help care for me. My mother says I was very close to my grandparents in those early days. When mom and dad went to work, it was my grandparents who stayed at home to feed me and play with me.

I was a spoiled child. My grandparents always bought me toys and cooked delicious Chinese meals: steamed buns, pork ribs, salted duck, and dumplings. Sometimes they took me into the city, where we'd visit museums and go to the zoo to watch animals. All in all, I was a very happy, content child, but there was one thing I desired more of. The neighborhood we had moved into was newly constructed and did not have many other families living in it. As a result,

there were few children my age to play with, and I wanted to make more friends.

Opportunity came one day in August, after I turned three years old. My mother sat me down and told me I was now old enough to go somewhere called “daycare,” where I would finally be surrounded by kids my age. She remembers the amazed look on my face when she told me we could all become playmates and have fun every day. To me, she said, nothing sounded better than making new friends while having my grandparents around too.

The daycare, which I still see whenever I drive around my hometown, is situated next to a place that always reminded me of a power plant with huge chimneys. A sign by its entrance reads “West Point Child Learning Center.” Around the building are patches of tall, leafy trees. Colorful playgrounds and sand pits with plastic tools and buckets dot its perimeter. On the inside, wooden cubbies for children's belongings line the walls. The classrooms, for some reason, are designed with protruding entrances that resemble the facades of houses, complete with windows and half-roofs. Down one long hallway are the rooms for the toddlers. Down another are the rooms for preschoolers and kindergarteners, the rooms my father took me to on my first day of daycare.

That morning, my excitement quickly waned. When my father and I got into his car to drive to the daycare, I noticed that my grandparents had not come with us. I questioned my father, and all he told me was that they couldn't go to daycare with me. My eagerness was suddenly replaced with dread, and my father tells me that when we arrived at the daycare, I seemed stiff as I walked. I had never been somewhere without my grandparents before. Surely, at least, my father would stay to accompany me.

But he did not. Once we arrived at the classroom, my father introduced me to the daycare teachers, explaining that they would take care of me for a while because he had to go to work. He recalls me clinging to him tightly. I did not want to be watched over by strangers in a strange

place, I had cried. I wanted to be home with him, my mom, and my grandparents. Though my father was just as sad as I was, seeing his daughter cry, he could only hug me and remind me to be good before walking out of the room. For a long time, I stayed there by the front of the door, bawling for my family. But no one came. No dad. No mom. No grandma. No grandpa.

After that first day, my father said I would have to get used to going to daycare every weekday. My grandparents were not permanent residents of the United States, and they had to fly back to China on an airplane within a few weeks. Grandma and grandpa would no longer be around to babysit me, and I could not be left at home alone. I could not comprehend what it meant for my grandparents to leave. I thought they were only going on a brief trip and would return eventually, just like how my parents came back from work every evening.

For nearly a week, I did not eat, drink, or interact with others at the daycare, nor could I calm down enough to take naps during nap time. Many children have some kind of difficulty when entering preschool for the first time, but the degree to which I had these problems made my parents believe that my separation from my grandparents was particularly rough. Later on, after I developed SM, they would blame themselves, thinking they had made a mistake in my upbringing. “We could have asked your grandparents to spoil you less or let you spend more time away from them,” they told me. “If we did that, maybe you wouldn't have had so much anxiety about going to daycare, and maybe that could have prevented you from getting selective mutism.”

I am not sure if they could have convinced my grandparents to step back at all; my grandmother was furious when she found out I was so upset about daycare. She did not understand why I had to go there if I was only going to be miserable. She asked my parents why she couldn't go into the classroom to keep me company and feed me foods I actually enjoyed.

She even proposed to take me back to China with her, so she and my grandfather could keep caring for me. My parents told her that firstly, the teachers would not allow it, and secondly, I had to learn to be apart from family in order to successfully transition into school. Everyone was sad to see me so down, but this was a necessary step in growing up.

Later that year in September, we drove all the way to New York to send my grandparents to the airport. As we checked in their baggage and led them to the security checkpoint, I cried and held onto them as long as I could. The time to part ways came much too quickly. Once the airport officials cleared them, they receded into the masses of other passengers, leaving me with red, teary eyes.

The next morning, when I woke up at home, I still hadn't registered that my grandparents were gone. My mother recalls that I had tried to search everywhere for them. I crawled on the floor, peering under the bathroom door to see if either of them were sitting on the toilet. I peeked into mom's closet, then dad's, and then ran to stare into the mysterious darkness of the basement. When I didn't find them there, I scampered upstairs to gaze into the equally mystifying attic. My parents forbade me from wandering into both these places out of fear for my safety, so instead of approaching, I called my grandparents' names. "*Wu Ming Gao? Zhou Qian Xia?*"

No reply. I ran to my parents, hot tears pouring down my cheeks. With heartbreak on their faces, they took me into their arms, saying we would go visit my grandparents in China eventually. For the time being, they brought me to our old apartment in the town of Bryn Mawr, where grandma and grandpa had helped raise me during my infancy, in hopes of cheering me up. I got to see the playground we used to romp around in and the Seven Eleven my grandmother and I would visit to buy snacks and drinks. These familiar sights were enough to make me feel better, but it took some time to get used to my grandparents' absence.

~\*~

My grandparents were only fluent in their motherland's language, so while they were still here, we mostly spoke Mandarin at home. My parents and I did know some English; mom and dad had to learn it and take the TOEFL in order to come to America for graduate school, and they passed what they knew of the language down to me as soon as I could start talking. After my grandparents left and I entered daycare—a primarily English speaking environment—I had to start using English more and more. Initially, my speech was rusty. I had not really exercised my English skills outside of my family, so the first few days I did not say much.

Over time, I got used to the language. My parents started speaking more English at home to train me. I listened closely when others talked. I read many books, from Dr. Seuss's *The Cat in the Hat* to Eric Carle's *The Very Hungry Caterpillar*. I repeatedly watched Disney films and sang along to tunes like “Bibidi-Bobbidi-Boo.” Perhaps more unusually, I picked up a lot of English by being obsessed with computer games. When I was one, my mother purchased a big, clunky Windows 95 so she could do office work at home. However, once we bought a few educational games such as *Reader Rabbit* and a *Berenstain Bears* game, the machine turned into my learning computer as soon as I figured out how to operate the mouse. I would gleefully shout words I saw and heard in the games to my parents. I soaked up so much information that I shocked my mother by pronouncing “Disney Enterprises” near perfectly when I was only about two years old.

Mom and dad both thought I was linguistically gifted. My daycare teachers also took interest in how chatty and outgoing I was becoming as I advanced through preschool and kindergarten. They wrote in a journal for my parents, “Helen has been pronouncing words more clearly and has been even more expressive than usual.” I was quite proud of my speech, and

every day, I babbled to all the staff and my friends about facts I learned and places I traveled to during family vacations. Everyone had to know that Niagara Falls was in Canada, and Niagara Falls was also really huge and really cool and sprayed my face with chilly water.

But as I went around talking and befriending others, I made a mortal enemy too. Brett was a white boy—short haired, gap toothed, and perpetually squinting. He said during introductions that he was from Texas, which gave me the impression he was somehow more American than usual; I had heard Texas was where the cowboys lived, and lots of American legends I knew talked about cowboys fighting bandits and Indians in the West. Yet unlike cowboys, who always seemed brave and noble, Brett was a bully.

On the fateful day, which started as a perfectly normal day, Brett approached me with a sneer on his face. I stopped what I was doing and frowned at him, tensing up immediately. From day one, this boy had been following me around, making faces at me and parroting anything I said back at me in a whiny voice, all for no apparent reason. What on earth did he want now?

“Hey Helen,” he called, “guess what?”

“Go away!” I cried. But he stepped forward anyway, grinning.

“You sound weird!” he cackled straight to my face. Before I could react, he stuck out his tongue, turned around, and ran away.

The moment was brief, yet his words etched themselves deep in my heart. He had made fun of an accent I didn't even realize I had. Never mind that Texans could have accents too. His words were hurtful in a way that I thought words could never be. Something dark and heavy wrapped around my throat and refused to let go. It was unnerving, and I cried and ran to the teacher.

The next thing I remember happening was this.

A few days later, I was playing Go Fish with a teacher. She asked for a card I didn't have, so according to the game's rules, I had to tell her to go fish. The thought of having to do so sent a strange chill down my spine, something I had never felt before. I opened my mouth. No sounds came out. I closed my mouth again. There was a heaviness in my neck. For a minute that felt like forever, I strained and tried to push those two simple words, go fish, up using my stomach. Yet they remained lodged in my throat like stones, choking me.

The teacher looked worried.

~\*~

Why did Brett's insult have such a powerful, lasting effect on me? Children lack social finesse, so it's not uncommon for them to make fun of each other. But unless it repeatedly happens, the fickle nature of childhood also means they tend to recover from the upset quickly. As I learned later, it is increasingly believed among researchers that kids who develop selective mutism tend to be predisposed to anxiety.<sup>1</sup> Specifically, their genes lead to a “decreased threshold of excitability in...the amygdala.” A structure in the brain, the amygdala is responsible for our fight or flight response, our feelings of aggression and fear. A decreased threshold of excitability means the amygdala triggers the fear response more easily, and reactions to fear tend to be more intense. This is supported by the fact that many selectively mute children demonstrate symptoms of severe anxiety: trouble sleeping, frequent tantrums, and extreme shyness, among others.<sup>2</sup> These children also usually have parents who have anxiety problems too, hinting at a genetic link.<sup>3</sup> This was probably my case; I was more sensitive to mockery than most kids would have been. And to this day, I'm still fighting other anxiety-related issues: I'm avoidant of conflict, I struggle with self-esteem, and often get caught up worrying about the future.

---

1 Cline and Baldwin 56

2 “When the Words Just Won't Come Out” 1

3 Cline and Baldwin 33

However, it would be too simple to say this was the only cause of my mutism. Like most illnesses and disorders, multiple factors can contribute to the development of SM. As it turns out, my parents' theory had some weight; many selectively mute children begin their mute behavior after some kind of difficult separation or rough transition, and they may continue to have trouble with any kind of change in the norm or routine after developing SM. This does not have to mean something as serious as a death in the family. It can be a parent resuming work after taking time off to care for the child, or moving to a new place.<sup>4</sup> In my case, my grandparents returning to China after being a constant presence in my life for two years probably helped spark my SM.

Additionally, I found out that kids from bilingual families are at greater risk of developing SM. When transitioning from home (where the first language is spoken) to school (where the second language becomes dominant), children may not feel confident in their ability to speak the second language and eventually become selectively mute in order to escape their anxiety.<sup>5</sup> For me, this was not an issue before Brett. However, after he mocked my voice, I became ashamed of the way I sounded.

My shame lasted all the way to the end of kindergarten, when it came time for all the kids to graduate and move on. We, along with our proudly beaming parents and teachers, gathered outside in a circle by the playground on a sunny June day. The teachers made a little speech about our time at the West Point Child Learning Center, talking about what we did, how we'd grown, and how we were now ready to go out into the even bigger world of grade school. It was supposed to be a joyful, triumphant moment. But my mother told me that when the teacher called me to receive my kindergarten diploma, I didn't move. I just stayed on the ground and started to cry.

---

4 Cline and Baldwin 61

5 Cline and Baldwin 22

The ceremony was temporarily suspended as my parents bent down to hold me and pat me. “Helen, why are you crying?” they asked. “What's wrong?”

“I don't want to stand in front of everyone,” I wept. My parents were puzzled. The crowd of people staring at us contained faces I had known for the entirety of daycare, with friends and teachers who I liked. Mother and father weren't sure why I was now unwilling to face them. After the ceremony concluded, as we drove back home in our car, my parents said, “It's okay Helen, you were just having a bad day.”

But little did we know, it wasn't just a bad day. It was only the beginning of something greater.

### Chapter 3

#### Mrs. Buck

*“It's feeling alone, because you're 'that kid who doesn't talk' and most people have never encountered anyone like you before, and they don't understand why you can't speak. It's not being able to explain why you don't talk, because even if you were able to speak to answer them, you don't fully understand it yourself.” - Alison, *Selective Mutism in Our Own Words**

“Double check, triple check, double-triple check!” In the time leading up to my first day of school, this became my mother's mantra for everything we did. When we went to Staples to buy supplies, we double-triple checked the shopping list. We double-triple checked my closet to make sure I had enough new clothes to represent a fresh start in my life. We double-triple checked that I knew our phone number and address by memory, as well as my bus number. Everything had to be perfect so I could get off to a good start.

On the morning of the first day, my mother roused me from sleep, got me dressed, helped me wash my face at the bathroom sink, and led me downstairs to the kitchen. My father was sitting at the dining table, reading the Wall Street Journal and watching Bloomberg Television. Breakfast was already prepared; the scent of scrambled eggs wafted through the room, drawing me to the meal. I sat down across from my father and ate the eggs and some cereal with milk, trying to focus on the sweet and savory flavors and the newscasters' voices instead of my pounding heart. I wasn't sure if it beat out of excitement or nervousness.

Once we were all fed, we got into our car and made a five-minute drive right down the road to Worcester Elementary School. Other days I would take the bus, but on the first day of school, my parents wanted to be by my side, partly to make more comfortable and partly to celebrate this milestone in my life. I held my breath as I looked out the passenger seat window, watching as we passed a busy intersection with a Wawa and gas stations to turn into the school's driveway. As Worcester came into view, my eyes widened. It was a very new looking building—long, tan, and two stories high, complete with big windows and an impressively spacious playground. Big, yellow buses lined up in front of the school, dropping off hundreds of laughing, screaming kids. Teachers stood outside, waving and smiling at everybody. I had never seen so many people in one place at the same time.

We parked and stepped out of the car. My parents carefully guided me through the noisy, vehicle-filled parking lot, holding my hands tight. There was a flagpole in front of the building, and we stopped there to take a picture of me standing before my new school. Then, my parents and I tried to walk through the doors, but one of the teachers approached us and told mom and dad that they could not go inside; I would have to separate from them here. Beaming proudly, my mother and father embraced me and kissed me goodbye. “Be good!” they said. “Listen to your teacher and enjoy your first day of school!”

I watched as they returned to the car and drove away. Part of me wanted to call them back and insist to the teacher that my parents should stay, but the other part was mesmerized by Worcester's grandeur, its foreignness, and all the excitement of the first day of school. I turned back towards the building and allowed myself to get swept into the crowd of excited children. I had to find room 1B, my homeroom.

It was on the first floor, down the hall to the right of the main entrance and the principal's

office. A cluster of children was already gathered there. An elderly woman stood by the door. Her short, gray hair and kindly, wrinkled smile reminded me of a grandmother. She shook hands with everyone and introduced herself as Mrs. Buck, the teacher. She invited all the kids to head inside the classroom and find their desks.

Inside was a big whiteboard that spanned nearly an entire wall, a wooden piano in the corner, and all sorts of motivational posters and educational charts on the walls. A few stuffed animals sat by the window, guarding shelves filled with children's books. There were at least fifteen desks facing the whiteboard, and it took me a few seconds to find the one with my name tag; my name was written in impeccably neat handwriting. Slowly, my classmates filled the other desks.

After making sure everyone was present, Mrs. Buck went to the front of the room and cleared her throat. "Hello everyone!" she said, in a soft, yet enthusiastic voice. "Who's excited for the first day of school?"

Some of the kids cheered aloud, and others raised their hands. A few did nothing and remained silent; I was among their numbers.

"That's wonderful!" Mrs. Buck continued. "I'm glad you're happy to be here. You all look like very bright and promising students, and I hope you'll enjoy being at Worcester. Now, there's a lot of us here, so how about we get to know each other a little better? Let's go around the room and have everyone say their name and something about themselves. It can be your favorite animal, your favorite color, or an activity you like to do."

She pointed at the first student in the first row. Right away, that familiar, terrible sensation rose up inside me, the feeling that my throat was closing up and my mouth was sealing shut. One by one, my classmates took their turns until Mrs. Buck's finger was aimed at me. I looked down

at my name tag. *Hi, I'm Helen*, I wanted to say. I pictured my lips forming the words, but no matter how hard I thought, I couldn't actually get them to do so.

There was an awkward silence. I could feel everybody's eyes on me, and the expectation for me to speak was palpable in the air. Eventually, Mrs. Buck gave me a sympathetic smile. "It's all right if you don't want to share anything now, Helen," she said. "The first day of school can be a little scary, but I hope we can help you feel more comfortable soon."

She went on to the next student, and some, but not all of the tension left my body. The unease that lingered in the pit of my stomach made me fidget with my hands and kept my gaze averted from the rest of the class. Even after the introductions concluded, I could not stop thinking about what was wrong with me, why I suddenly felt like a zipper had been melded to my mouth and pulled tightly shut. I did not say a single word the entire day.

~\*~

Weeks passed. Each morning, as people streamed into the classroom, I couldn't say hello to anyone. I never spoke when Mrs. Buck asked me a question in class, nor did I ever raise my hand to speak. When the school day was over and teachers watched us to make sure we boarded our buses safely, I could not say goodbye to all the faces I recognized. I couldn't speak up if I felt ill. When we rose for the Pledge of Allegiance every morning, I put my hand over my heart, yet I couldn't utter the words that signified my loyalty to America.

Sometimes in the middle of lessons, I retreated to the corner of the room to read books instead of completing my assignments. Other times, I got out of my seat while Mrs. Buck was talking and paced around. It was an effort to avoid activities where I might have to speak, but when Mrs. Buck reported this to my parents, they just thought I did not quite understand the rules of the classroom yet, having come from a kindergarten that was not part of a school.

Music class was particularly agonizing. My selective mutism, though I did not know it was called that yet, made me not only afraid to sing, but also embarrassed to express myself through playing instruments and dance, as if I'd be judged for my performance the same way Brett judged the way I sounded. Children with selective mutism oftentimes aren't just mute; they are also behaviorally inhibited, freezing up when expected to perform and struggling with expressing themselves through body language.<sup>1</sup> I spent most of the time facing away from the teacher in my chair, stone still and unresponsive, unwilling to move my body to the chicken dance or blow out notes on my pink, plastic recorder. Sometimes, when I was especially tense, I closed my eyes and covered my ears to shield myself from the music, which had become a symbol of unmet expectations in my mind. Eventually, the teacher wrote a progress report to my parents giving me an “unsatisfactory” grade, the lowest mark, saying “she does nothing to succeed in music.”

After a while, the other kids caught on to my strange silence. They began calling me “the girl who doesn't talk,” whispering about me behind my back while we walked through the halls. Whenever I heard the nickname, I tightened up and tried to put distance between myself and the gossipers, realizing perfectly well that my lack of speech was weird and hating the fact that they were drawing attention to it. However, my classmates would inevitably approach me, asking me to confirm or deny their theories on why I didn't speak, such as:

“Are you shy?”

“Do you have a weird accent?” (This brought up bad memories. Even today, I get mildly annoyed when people mention I pronounce “th” like “s”.)

“Do you know English?” (An extremely baffling question, as my classwork showed that I

---

1 “When the Words Just Won't Come Out” 2

could read, write, and spell as well as the best of them.)

“Did you take a vow of silence?” (Even more baffling, as I couldn't imagine any circumstance where anyone would willingly subject themselves to the frustration of being unable to speak.)

Most of the students were probably just curious and didn't mean to bother me. But without knowing what to call my condition, I had no explanation for why I couldn't talk, and I usually just nodded yes to being shy before walking away quickly for the sake of getting my classmates off my back—even though I was fine socializing with others when they weren't nagging me about my speech. Some accepted this and started to leave me be, at best inviting me to join them on the playground to coax me out of my shell; these kids became my friends, though I still did not talk to them. Others were not as convinced and I stayed away from them since I knew they'd heckle me again. Such is the tragic trap of SM; you have a problem, and you want nothing more than to break free from it, but you literally can't tell others that you have it, so they don't know how to help you, and if they're making you uncomfortable or being downright abusive, you can't ask them to stop.

I never reported any of these problems to my parents. If I had no good explanation for why I didn't talk, then why bring it up at all? Mentioning it would only make them worry and ask me to tell them what was happening, and I already had quite enough of kids wondering what was wrong with me at school. Instead, whenever my parents asked me how my day went, I would share a fact I learned or mention an activity the class did, avoiding the elephant in my mental room.

So, the first person to tell my parents I wasn't speaking was Mrs. Buck. A whole marking period passed, and the time for parent-teacher conferences came. At night, my mother and father

drove with me to school and went to meet Mrs. Buck in her classroom, letting me romp around in the hall in the meantime. I wasn't privy to their conversation, but they told me later that one of the first things that happened after they sat down was that Mrs. Buck asked, with a grave expression, "Does Helen talk at home?"

My parents' faces filled with confusion. They glanced at each other and then back at Mrs. Buck. "Yes, she's very talkative!" they said. "She's always telling us about her day and explaining her drawings and stories. What's wrong? Did something happen? Is she not talking in class?"

"She hasn't said a thing out loud," Mrs. Buck replied. "Sometimes it seems like she's trying to whisper something to me, but I can't hear her and have to read her lips. She doesn't talk to any of her classmates. That's why I was wondering if she also acted this way at home."

Mrs. Buck and my parents concluded that I was simply adjusting to elementary school slower than most other kids, having moved from a relatively unstructured daycare experience to a more structured classroom environment. And, like some of the children, they also thought that I was just shy at school. When we drove home after the conference, mom and dad gave me a gentle reminder that I wasn't in daycare anymore, so I had to participate in class, try to raise my hand, follow all the rules, and respond to the teacher. Still uncertain of how to explain my anxiety, I just nodded. I understood what I was supposed to do, but could I actually do those things?

~\*~

In theory, it's not all that hard to diagnose selective mutism. The basic criteria are that the person speaks in at least one setting and fails to do so in at least one other (though SM can progress far enough that the person fails to speak in all settings) for a minimum duration of one

month. Furthermore, the silence cannot be explained by a lack of fluency in the language or better explained by communication, developmental, and psychotic disorders.<sup>2</sup> Regardless of the ease of diagnosis, none of us had any idea selective mutism even existed while I was in first grade. How could we identify a condition if we had no knowledge of it?

My situation was also an example of another problem with SM diagnosis and awareness. In addition to mistaking SM for normal shyness, Carl Sutton, owner of the SM support website iSpeak, writes, “transient mutism among anxious and sensitive children who are just starting school is, in fact, relatively common.”<sup>3</sup> Therefore, parents and teachers may expect the child to outgrow their silence eventually. This is an incorrect assumption that can unfortunately lead to children receiving little to no help for their struggles. It may take years for children to finally get a diagnosis and intervention.

Even though my parents and teachers did not recognize the extent of my problem, Mrs. Buck still made an effort to increase my comfort in the class and never punished me for failing to speak, nor did she ever pressure me to speak. One of my favorite memories from first grade, ironically, involves Mrs. Buck leading the entire class in sing-a-long songs. On certain days, she would dim the lights and put lyrics to tunes like “Big Rock Candy Mountain” and “Little Bunny Foo Foo” on the projector. She'd head over to her piano, strike up a chord, and cheer for everyone to sing.

Of course I couldn't sing along, but the difference between Mrs. Buck and my music teacher was that Mrs. Buck never made me feel like I *had* to sing. She held the opinion that it was more important for me to develop an appreciation for music than talk. I could sit with my classmates on the floor and simply absorb the sounds that rose up, the chorus of voices and the

---

2 Hua and Major 115

3 Sutton and Forrester 69

piano's clear, ringing notes. Sometimes, Mrs. Buck even invited me to sit next to her at the piano, a privilege she offered no one else. I would watch, fascinated, at how her hands, wrinkled but lithe, hopped from key to key like grasshoppers.

She wasn't aware of it, but Mrs. Buck's philosophy was one that worked exceptionally well with selective mutism. Instead of confronting me about my silence, she released all expectations for me to talk and focused instead on making me feel included in the class. It is thanks to this that I gradually became able to enjoy most of first grade despite its difficulties. Even after I switched schools two years later, I remembered Mrs. Buck's gentleness and always gave her a big hug on the few occasions I saw her.

## Chapter 4

### Problem Child

*“If you want to stump every education professional that you encounter just mention Selective Mutism and ask what they plan on doing to accommodate your child. You will be looked on as though you have three heads. But in defence of these teachers, psychologists and social workers, there was not and there still is not enough information about this disorder for them to fully understand the scope of the problem, let alone attempt to address the needs of your child.” - Ann,*

#### *Selective Mutism in Our Own Words*

Had I stayed with Mrs. Buck after my first year of school, I feel like I may have made some real progress with talking. I became comfortable enough around her that on rare occasions, I could lean over and whisper into her ear. Perhaps I could have started speaking to some of my classmates too; there were a few girls, like pretty CJ and sporty Maggie, who I became friends with and played with outside of school.

Unfortunately, the way my elementary school worked, and the way many elementary schools in the United States work, wasn't the ideal situation for my selective mutism. When kids moved up a grade, they would receive an entirely new teacher and many, if not all, new classmates. One particularity about my own SM (though this is also true for many others) was that I could never talk to people I just met. This meant that entering a totally different class basically erased my steps on the path towards speaking out loud and socializing, sending me back to square one. My mother often lamented this aspect of American schools; back in China

during her day, all children in a single class would stay together for the entirety of their grade school education, and she felt my anxiety would have been reduced if I had this kind of familiarity.

At the time, however, I wasn't too worried. I had survived and even enjoyed class under Mrs. Buck's kind and patient care, and I thought I could expect the same treatment from my second grade teacher. As I walked upstairs to find Mrs. Cain's room on the first day of the school year, I had a smile on my face and a skip in my step.

The new classroom did not look too different from my old one. It was just as colorfully decorated, though there were fewer stuffed animals, and there was no wooden piano to make music. The only thing that stood out was a poster on the wall, which proclaimed, in yellow lettering, "silence is golden." I paused to consider this. How, I wondered, could my silence possibly be golden when it made everything harder?

I found my desk and sat down. As the class trickled in, I scanned their faces to see if I recognized anyone, but I didn't. Moments later, the teacher arrived and walked to the front of the room. Mrs. Cain was a large woman, and when she gazed upon the class through her glasses, I felt like a squirrel being watched by a hawk. She looked middle aged, with some streaks of gray hairs on her head and the beginnings of wrinkles on her cheeks. She introduced herself wearing a neutral expression; her voice did not have the warmth that Mrs. Buck's had.

Now it was our turn to say our names. I still hated this part of the early school year, this moment where everyone's eyes were guaranteed to be on me. The other students taking their turns felt like a countdown to doom: Rachel, Nathan, Sarah...

Mrs. Cain's stare landed on me. My lips pried open a tiny bit, and I tried to force something, anything, out of my throat, but all the words died on my tongue. The teacher leaned

forward and cupped her hand around her ear. “What’s that?” she asked. “Can you speak a little louder?”

I could not. I could not. Shriveling underneath everybody’s gaze, I clamped my mouth shut again and looked down at my desk. Seconds of deathly silence ticked past. With a sigh, Mrs. Cain skipped over me and moved on.

~\*~

“Can she talk?” That was the question Mrs. Cain posed to my parents after I failed, over and over, to speak in her class. They gave her the same response they gave Mrs. Buck, but their confusion was growing. It was becoming evident that the Helen my parents knew at home was not the same Helen my teachers saw in class. And because I had already spent a year at Worcester, the theory that I was just adjusting to school more slowly than other kids were was basically null.

No one knew what to do. Mrs. Cain asked my parents if there was any way to prove that I could talk, or any way to get me to talk. After deliberating, they decided to try showing the class a video of me speaking, thinking that if my classmates and teacher heard what I sounded like, I would become more willing to start talking in real life. I agreed to the idea, but I couldn’t help feeling nervous about it. What if everyone thought my voice was weird?

So, I went to school one morning carrying a VHS tape from home in my backpack. Though it weighed nothing, its presence in my bag seemed to press down uncomfortably on my shoulders. I headed to the classroom and waited until everyone arrived, holding my breath as I watched the stream of kids slowly trickle in. Finally, once all the students were present, Mrs. Cain stepped up to the front of the room and cleared her throat.

“Class,” she began, “we’re going to start off our day with something special. Helen has

agreed to share a video of herself because she wants to let everyone know that she can talk. Let's all go sit in front of the television. This is very important for Helen, so please, no laughing, giggling, or chatting while the video is playing.”

My classmates silently shuffled over to the TV, a big, clunky, black CRT perched atop a rolling stand in the corner of the room. They settled into a cluster on the floor while I handed the tape to Mrs. Cain. As she turned on the TV and inserted the VHS, my heart began beating faster. I tried to swallow the lump forming in my throat and sat down near the back of the group of kids.

The blue screen flickered to life.

As grainy and poorly lit as it was, I recognized the recording. It showed the time when I went to my daycare friend Elizabeth's birthday party. A bunch of girls and a few boys were gathered around a wooden picnic table, surrounded by their parents and balloons. The table was littered with paper plates, plastic utensils, and napkins, all covered in the remnants of frosted cake. Every child wore a party hat and carried a goodie bag featuring Elizabeth's favorite book character, Madeline. Elizabeth's mother was standing in the background, and you could hear her counting down from three. At “go!”, all the kids opened their bags at the same time and pulled out the same goodie, a felt craft kit that would let us make our own Madelines and dress her up in her signature yellow school outfit.

The party exploded into joyful screaming. Some children ran up to their parents to show off the Madeline kits, while others ripped them open right away. It took a moment for the adults to get everyone settled again. Once the noise calmed down and the kids were reseated, Elizabeth's mother began demonstrating how to make our Madelines, holding up squares of felt, cutting them with scissors, and gluing them down onto a piece of cardboard.

The camera panned over to a small Asian girl with a bowl cut and a white, flower

patterned dress—me. My eyes were completely focused on the yellow felt in my hand, which I was cutting into the shape of Madeline's hat. Over the chatter, my own mother's voice rang loud and clear. “You have fun, Helen?” she asked. “What are you making?”

Past Helen looked up into the camera and grinned. Her gaze injected cold dread into my veins. I could only look on, frozen, as her mouth opened and her tongue rolled to form the beginnings of a sentence.

“I'm cutting out Madeline's hat!”

I shot to my feet and covered my ears. I didn't look at anyone as I ran to the opposite corner of the classroom, screeching like a banshee, hoping to drown out the speech coming from the television. There was a cart of textbooks in that corner, and I ducked behind it to hide from the stares that I was sure were coming from everyone. Hot tears welled out of my eyes and dribbled down my cheeks. I dared not stop crying, dared not unplug my ears, because if I did, I would again hear the sound of words coming from my past self's throat.

Lost in the haze of terror and tears, I did not notice when Mrs. Cain ended the video. I only felt her looming presence suddenly appear behind me, producing the same tension in the air as one might feel before a thunderstorm. “Helen,” she said, “the video is over. You can come out now.”

I didn't budge. I didn't want to see the reactions. I didn't want to know what people thought of a girl who could shriek and sob as if the world was ending, yet couldn't form a single word when asked to, even though she was clearly able to when she was younger. Shaking, trembling, I curled up more tightly into myself. It was as if I had been violated and had a part of myself I didn't want anyone to know about forcibly exposed for the world to see.

The disappointment coming off of Mrs. Cain was palpable. “If you're not going to get

up,” she sighed, “then I'm calling the counselor to come get you.”

~\*~

I was a problem child. I had never been one before, but in an instant, I became one. Because I still didn't speak in class even though the video showed I could talk to other people, Mrs. Cain interpreted my silence as a refusal to speak. Likewise, some of my classmates assumed I didn't talk to them because I disliked them. I remember one day we were standing in line in the hallway, waiting to enter a classroom, when a girl who always tried to converse with me came up and asked, in an upset tone, “Do you hate me?” Nothing could have been farther than the truth. Whenever Mrs. Cain asked a question I knew the answer to, I desperately wished I could raise my hand and share my knowledge aloud. Whenever a classmate wondered what I thought of them, I wanted to cry, “No, I don't hate you!” But SM's jaws would inevitably clamp down on my throat and keep me from proving my abilities and character. The warmth and acceptance I felt in Mrs. Buck's class was quickly replaced by unfriendliness.

It started with Mrs. Cain preventing me from using writing to communicate. I had gotten used to responding to Mrs. Buck using written notes, but now, if there was anything I wanted to say, Mrs. Cain demanded that I use my voice. Every time I had to use the bathroom, I wrote down a polite request for permission and brought it to Mrs. Cain, only to have her hardly even glance at the paper. “Read it,” she'd order. She'd only let me go out of exasperation after I stood petrified and silent for minutes, head hanging.

It felt even worse when she called on me in class. “Can you tell me the definition of this, Helen?” she'd ask, pointing to whatever vocabulary word she had scrawled on the whiteboard. If I wasn't comfortable enough to talk to her one on one, then there was no way I would say anything with the entire class focused on me. She'd interrupt me if I made any attempt to bring

pencil to paper. “No, Helen,” she'd sigh. “I want you to *say* it.” Countless minutes of class time were lost as I tried to mouth the answers, time that easily could've been saved if she just allowed me to write. According to the school, this lost time only happened because Mrs. Cain was trying to be “inclusive.” Worcester sent a report home to my parents that read, “The teacher may need to take a significant amount of time to try to understand what Helen is mouthing. This usually causes the lesson to come to a standstill as Mrs. Cain attempts to include Helen in the discussion.”

Yet it wasn't enough to take away my writing. Since I couldn't get anyone's attention by calling their name, I resorted to tapping people on the back or shoulder. At best, they turned around and asked me what I needed. Oftentimes, though, the other person would tell me to keep my hands to myself, and this happened enough that Mrs. Cain started keeping an eye out for me touching others. Mrs. Cain would even tease me if I did this to male students. “Ooh, looks like Helen has a boyfriend!” she'd laugh. I was made to feel ashamed of something I needed to do to get by. When I told this to my parents, my father found her reaction rude and inappropriate, and my mother was incensed by the “hands, feet, and objects to yourself” rule in general. “China never had this stupid 'no touching!’” she told me, anger contorting her face. “It is against children's nature! Children want and need healthy contact with people. Yes, there is some bad touching that should not allowed, but you do nothing wrong!”

Looking back, I am frustrated by how blatantly wrong this treatment was. It's like forbidding a deaf kid from using sign language, denying a blind child a cane, or telling a student who stutters they are interrupting the class because they can't talk correctly. But students of these groups, at least, have relatively well known conditions with established support systems they can turn to if they are ever mistreated or refused accommodations. Children with selective mutism

don't really have such privilege since SM is widely unknown.

This is troubling because poor handling or outright bullying of students with SM by teachers seems more common than it should be. Alison, who I've quoted before, once had a teacher who would yell at her in front of the entire class and make her cry, to the point where she requested a class transfer. Another woman, Vivienne, recalls that her teacher not only gossiped with other students about her—students who called her a “retard”—but also told her parents she was “a very slow learner” and “would never be able to cope with maths.”<sup>1</sup> In a study of 13 children with selective mutism, about half of them “had been threatened with dismissal from school because of their refusal to talk.”<sup>2</sup> None of this should be acceptable.

By October, my relationship with Mrs. Cain had become a vicious cycle. My anxiety made me unable to speak to her, which in turn led her to pressure me into talking. Since she was pressuring me, I started thinking that she was cold and didn't understand me, which only made me even more anxious and afraid around her. It all boiled over on the fourth of the month.

In the morning during group time, Mrs. Cain instructed everyone to form a circle on the carpet and share stories of what we did recently. As the students took their turns, I felt a deep, red rage rise through my body; I knew Mrs. Cain would demand me to talk, and I was sick of her doing so. Before she could even call on me, I burst into tears and fell on my side, kicking my legs out in every direction, feeling them strike other children in the circle. “Helen!” Mrs. Cain shouted, glaring from behind her glasses. “Stop it right now!”

I didn't care. I didn't care. My leg flew out and hit Vincent, the boy who not so long ago stole my pencil and got away with it because I couldn't tell the teacher what he did, and he howled in pain. The other children recoiled from me, the freak, the wild animal. “Helen!” Mrs.

---

1 Sutton and Forrester 77, 144

2 Cline and Baldwin 31

Cain yelled again, with even more venom in her voice. “I’m going to call Mrs. Broadham!”

Mrs. Broadham. The lady from the principal’s office. My flailing limbs halted and dropped to the ground. Mrs. Cain commanded me to get up, grabbed my wrist roughly, and walked me to the classroom door. There was a telephone on the wall nearby. She picked it up and dialed Mrs. Broadham. Mrs. Broadham, who I would be sent to at least six more times throughout the year, whose room I became intimately acquainted with because according to Mrs. Cain, I didn’t respect teachers, didn’t respect personal space, and didn’t respect the right for others to learn. Mrs. Broadham, who really was a nice lady, but became someone I dreaded seeing. Mrs. Broadham, because I was the problem child.

~\*~

For years I demonized Mrs. Cain in my mind. I couldn’t understand how she handled my situation so harshly, especially compared to Mrs. Buck. She’s still not one of my favorite teachers, but in hindsight, I can sympathize with her more. Since speech is such a natural part of our lives, it was probably difficult for her to wrap her head around the idea of someone being afraid of it. I can also see why she misinterpreted my selective mutism as a deliberate refusal to speak. She knew I could talk to my parents; I could even whisper in their ears right in front of her. But because I never uttered a word directly to her, and because there were no other easily discernible triggers for my mutism (I simply was mute with everyone excluding my parents and certain close friends, no matter where I went.), she likely assumed that *she* was the source of the problem and took it personally. Hence, the accusations that I didn’t respect her and was holding up class purposefully.

This way of thinking was not particular to Mrs. Cain either. Misconceptions were so widespread that prior to 1994 (the year before I was born!), SM was called “elective mutism”

and defined as a “persistent refusal to talk” in the DSM, one of the most well-known and widely used documents in the entire healthcare industry.<sup>3</sup> If the American Psychiatric Association got it wrong, then it's no shock that teachers, psychologists, and the average person didn't understand SM well either. Stubborn, attention seeking, rude, manipulative, and defiant are all ways people have described children with SM. Unfortunately, even though the DSM entry has since been corrected, misunderstandings still run rampant, and everyone suffers for it.

Interviews with therapists and teachers show they often feel angry, incompetent, and even threatened because they have no clue how to address the lack of speech.<sup>4</sup> One father named Mark believes that his teenage daughter, Nicola, could have avoided having breakdowns and suicidal thoughts “if only...teachers had not marginalized her” for her SM. A mother named Julie, whose daughter Justine has SM, could not get Justine assessed for Autism Spectrum Disorder because the Social Communication Disorders Unit at the hospital she visited said Justine “refused” to communicate with them. Julie also comments that “parenting a child with SM can be pretty lonely,” as she lost a friend after the friend said to her, “I won't be coming round anymore because [Justine] obviously does not want me there and behaves like an animal hiding under the table when I come in.”<sup>5</sup>

So, it is clear that a lot of work can still be put into dispelling myths about SM, as well as making more people aware that SM exists at all. With less confusion surrounding the nature of the condition, teachers and therapists will be able to work with people who have SM more effectively, saving all parties a lot of heartache. I suppose Mrs. Cain really was trying her best and had good intentions that devolved into frustration and poor methods. If we lived a world that gave her more support and training for SM, maybe Mrs. Cain and I could have been friends.

---

3 Cline and Baldwin 13

4 Cline and Baldwin 30, 31

5 Sutton and Forrester 208, 210

## Chapter 5

### The Intelligence Test

*“Children with selective mutism have been found to have higher rates of a variety of developmental conditions. In a sample of 54 children...68.5% met the criteria for a diagnosis indicating a developmental disorder or delay compared with only 13.0% of the control group. Children with selective mutism had higher rates of elimination disorders, motor delays, and exhibited a lower mean performance intelligence quotient on cognitive testing. Half of the children with selective mutism met the criteria for one or more communication disorders, and many additional studies have provided evidence of underlying speech and language deficits...”-*

*Alexandra Hua and Nili Major, Selective Mutism*

As second grade progressed, my prognosis grew grimmer. I had not just stopped talking at school. I also started to fall silent in other settings and situations. If my family went to dinner together, I could not tell the waiter my order. If I went to my friends' houses, I screamed and laughed and conversed with them, only to clam up whenever their parents walked in the room to check on us. I never spoke to the instructor at the swimming lessons my parents put me in. If we were walking around in public areas, I had to whisper in my parents' ears, afraid of passersby hearing my voice.

Then one day, while I was in Mrs. Cain's classroom, there came a knock on the door. Mrs. Cain went to open it, and in the threshold stood a stranger, an elderly man dressed in a suit, carrying a clipboard. “Hello,” he greeted. “Is Helen Tang here?” His voice was calm and steady,

a voice that reminded me of the one my doctor used when talking to me.

I did not particularly like going to the doctor, and I was always wary whenever someone came asking for me since it was usually to put me in time-out for not speaking. I rose from my desk and walked up to the man very slowly, wondering what kinds of horrible things he had written about me on his clipboard. He extended a hand. I hesitated before shaking it. The man smiled. “Hi Helen,” he said. “It's nice to meet you. My name is Dr. Sherman. Could I take you out of class for a while? The school would like you to take a special test. I already talked about it with your teacher, and I promise it's not scary.”

I stared at him, confused, but also relieved that I was not in trouble. I could not think of why I had to do this; I wasn't feeling sick. Taking a deep breath, I followed Dr. Sherman downstairs and to the other end of the school, where he led me to a room I had never seen before. Instead of desks, it had long tables with rolling chairs on either side. The space seemed rather sterile, with no colorful posters or cute stuffed animals like the classrooms had. There were no chalkboards, but there were bookcases full of complicated looking, encyclopedia-sized tomes, texts meant for adults, not children. No one else was inside. The only sound was the occasional car driving by the window.

Dr. Sherman invited me to take a seat at the table. On its surface, there were several black binders, along with sharpened pencils, sheets of notebook paper, several maroon booklets, and a calendar-like object. The booklets and calendar read “Woodcock-Johnson.” My confusion grew. Was this doctor not giving me a physical examination?

“This is an intelligence test,” Dr. Sherman explained, taking a seat opposite of me. “It's going to test you on things like math, reading, and writing, but it's a little different than what you're used to in class. All you have to do is follow my directions and answer the questions. Do

you understand, Helen?”

I nodded. As long as I didn't have to speak, I had no problems finishing exams. Dr. Sherman pushed the “calendar” towards me and flipped it open, revealing it to be a series of cards with problems on it. The problem sets were full of pictures and puzzles, fill-in-the-blanks and patterns. Though Dr. Sherman explained each section with deliberate slowness, all the solutions came to me very quickly, and filling in my answers was an oddly enjoyable task.

An hour or so later, we were all finished. Dr. Sherman collected all the materials on the table and thanked me for my time. He escorted me back to Mrs. Cain's room, where the rest of the school day continued on as usual. I felt confidence in my performance, but I was still a bit mystified. What, exactly, was all that for?

~\*~

The goal of the test would only become clear to me years later, when I interviewed my parents about this part of my life. Prior to the exam, during a parent-teacher conference, my parents, Mrs. Cain, and Mrs. Broadham had met to discuss my behavior and performance in school. Mrs. Cain was dumbfounded. My lack of response to her in class had given her the impression that I was not paying attention to her teaching, yet my grades, barring participation points, were superb all around. I mostly got As and rarely ever dropped below a B. I can imagine her face wrinkling in frustration as she related this to my parents. “I think she might be playing dumb,” she said, “to get attention or bother me on purpose.”

Mrs. Broadham had a different concern. “It also could be that Helen has a developmental or learning disability,” she suggested. “Given her grades, I don't think it's likely, but her poor social interactions still worry me.”

Now I can picture my parents furrowing their brows, frowning hard. “We don't think that

sounds right,” they replied. “As you said, Helen's grades are very good. She's always been very curious and really enjoys learning. We do not think she has a learning disability or pretends to be dumb. Maybe her classes just aren't challenging enough to keep her interested. And Helen is very social outside of school! She has lots of Chinese American friends she does talk in English with, and she never behaves badly with them or their parents. We *know* she is a smart and nice girl. We just don't know why she has such a hard time at school.”

The teachers were not necessarily wrong to be concerned. Even if they had no awareness of selective mutism, SM can be comorbid with a variety of other conditions, particularly autism spectrum disorder.<sup>1</sup> Recent research suggests the amygdala, the part of the brain responsible for SM's fear and anxiety, may also be responsible for the various emotional and social impairments found in people with ASD.<sup>2</sup> Having one of these disorders alone can mean a hard time socializing; those with both often remark that they experience double the struggle in social situations, with some problems falling under their ASD and others falling under their SM, or with the two complicating each other.

It's worth noting here that there is a debate about whether or not SM should be considered a category of autism spectrum disorder. As someone who had SM but was never diagnosed with autism spectrum disorder, I disagree with this categorization, as it runs the risk of creating further misunderstandings of why people with SM act the way they do. If you look at a child who only has SM, they “interact just fine, with a full range of emotion, and awareness of social interpretation” in situations where they feel comfortable. They only exhibit mutism when they are anxious. On the other hand, a child with autism will “have a hard time interpreting subtleties

---

1 Wong 23

2 Zalla and Sperduti 1

of social interaction, whether or not they're in comfortable or uncomfortable settings.”<sup>3</sup> This distinction is further supported by those who have both SM and ASD, even though they may sometimes feel like their problems “mix” together. A woman named Sonja says she only learned she had Asperger's when she realized “some of what [she] was experiencing didn't seem to come under the heading of SM.” Two other women named Wendy and Lorraine say they feel different from other people with Asperger's because their inability to speak is much more pronounced, making them stand out from their peers who only have ASD.<sup>4</sup> Oddly enough, under the current iteration of the DSM, it is “not technically possible...to be diagnosed with both selective mutism and autism.”<sup>5</sup> Considering that people with both do exist, this seems like an oversight that should be corrected in order for these individuals to be better described and treated; parents have reported that unfortunately, “services for AS tend not to cater for people with SM, even though the two conditions commonly exist together.”<sup>6</sup>

So, my intelligence test was primarily meant to screen me for autism spectrum disorder, though it would have picked up other developmental disorders or learning disabilities as well. A month or so later, when the results came back, all the theories the school staff had were immediately proven to be incorrect. My IQ was remarkably high for my age, higher than anyone had expected. Ironically, some of my best scores were on the vocabulary and reading comprehension sections of the test:

- *“In the spelling area, where Helen had to spell a target word based on its meaning as used in a sentence, she obtained scores comparable to the fourth grade level and was even able to correctly spell such words as 'definition' and 'loyalty'...”*

---

3 Dickstein

4 Sutton and Forrester 170, 173, 178

5 Dickstein

6 Sutton and Forrester 184

- *“When Helen had to read a short passage and then answer the question that was written at the bottom of the page, she obtained results that indicate that her reading comprehension level is at the middle of sixth grade. She read each paragraph very rapidly and answered the question by writing the answer down almost immediately. It appeared as if she just skimmed the material, but her answers were almost always correct.”*

The report concluded that my teachers should be reassured that I understood their lessons, even if I didn't talk. Some teachers, upon reading my results, even joked that I didn't talk because I was “too smart.”

Still, there was something wrong with me. Dr. Sherman's notes read, “Helen displays oppositional behavior at times and has very weak social skills...difficulty staying on tasks and often wanders or crawls around the room.” The test results assigned me the disability category of “emotional disturbance,” but it didn't get more specific than that. A more concrete possibility was only presented once my parents and teachers gathered to discuss my test. Everyone was again sitting around a table in a conference room at school, this time with Dr. Sherman present. And this time, it was the adults, not me, who fell into a dead silence.

“What did you say?” my parents asked, staring. “Selective what?”

“Selective mutism,” Dr. Sherman repeated. “I believe your daughter has it, and I urge you seek help for her.”

That day was the first time my parents had ever heard of the condition. It did not sound real to them, and their initial reaction, all too common among parents of selectively mute kids, was confusion. At the same time, it was the only good lead they had, the only thing that sounded like it plausibly pertained to their daughter. Within the next few days, I watched as stacks upon

stacks of paper accumulated on our tables and nightstands at home, all journal articles and news reports on SM my parents had printed out. They asked me to read some of them, wanting to know if I thought the situations described in the documents sounded like mine or not. And they did. They all did. Slowly, I realized that the terrible force sealing my vocal chords up had a name, and that I was not the only person in the world struggling with it.

My parents were quick to find a psychologist. The first one they contacted, an older man in the nearby town of Blue Bell, was offered through their health care plan from work. We went to his clinic, but I have very little recollection of both the place and visit, and for good reason. The gentleman had no knowledge of selective mutism at all. He had never even heard of it. He could only offer my parents a referral to another psychologist in Bryn Mawr who had more experience with children, and that was our first and last meeting with that particular psychologist.

The person he referred us to was an elderly woman who was also a professor at Bryn Mawr College. Her clinic I remember a little more of; it had a lobby in the front with a few chairs and toys for children to play with, and a hallway led from there to a quiet room in the back, where she saw and worked with her clients. Her appearance I vaguely remember too; she was small and skinny, with short, graying hair that curled around her cheeks and round glasses. She and Mrs. Buck were probably around the same age.

To my parents' relief, she claimed to have treated six different children with selective mutism. We started going to her clinic twice a month for about half a year. During our appointments, she'd take me to the back room with my parents, and she'd lay out a board game called "Stop, Relax, and Think" on the floor. The board featured a winding road with colorful tiles and red stop signs all over it. The box for the game had a cartoon turtle on the front.

Looking it up now, the box also reads, “a game to help impulsive children think before they act.”

I can understand the logic behind the psychologist's choice of game. It is quite common for children with SM to have behavioral issues; not only do they feel frustrated about being unable to talk, they also, as children, have not developed enough social experience or self-awareness to assess the properness or consequences of their reactions to frustration.<sup>7</sup> I did act impulsively sometimes due to the anxiety and stress SM made me feel, including throwing violent tantrums and, more bizarrely, sniffing peoples' belongings like a cautious dog. Perhaps the professor could have helped reduce these behaviors, but that would not have actually treated the underlying problem.

Of course, at that age, I little idea of what would or would not help me, so I went along with the treatment and played the board game with the professor for thirty minutes per session. I was never enthusiastic about the game. Much of it involved saying things aloud, such as cards that told me to talk about my feelings or repeat certain words over and over until the psychologist told me to stop. Whenever I drew one of these prompts, I felt the familiar sensation of that dark force strangling my throat, and I stared at the prompts without uttering a word. The most the psychologist ever got out of me were vague, simple sounds, “mmms” and “errs” and “rrrghs.” It didn't matter how kindly she asked me to speak.

The psychologist had visited my school to distribute information about selective mutism to my teachers, which helped my reputation there somewhat, but towards the end of our time together, even she began to doubt if that was really the problem I had. We had made so little progress over so much time that she started to share the same theories Mrs. Cain had about me, despite the fact that she had never tried any other types of therapy outside of the board game.

---

<sup>7</sup> *Easing School Jitters for the Selectively Mute Child* 24

“Well,” she told my parents one meeting, “perhaps Helen does have a problem involving oppositional and controlling behavior. Maybe it's not selective mutism.” She recommended my parents to put me on medication instead, and they thanked her for her efforts and no longer took me to her. We had hit a dead end; we had no idea who else to turn to.

Still, my parents did not give up. They continued to meet with staff at my school and laid out a plan for my future education. They began talking about relocating me to a different elementary school in the district, Woodland, because of my unique needs. I was what is called a “twice exceptional,” a child who is intellectually gifted but also has a disability. Worcester had a gifted program, but its relative newness compared to other schools in the district meant it did not have a well-developed special education program yet.

At the mention of the term “special education,” my parents stopped the teachers. “But you just said Helen is gifted,” they said. “She does not have a mental deficiency. If she is put into a class with those kinds of kids, wouldn't that just slow down her progress? They do not learn or socialize at the same level she does.”

My parents had this concern because they only knew of the Chinese special education system from back in their day, which focused exclusively on children with intellectual disabilities. The teachers explained that special education in the United States was different; in the U.S., special education also helped children who had social and behavioral difficulties. With the special education program, I'd receive an Individualized Education Program (or an IEP), which would include a set of goals and special accommodations tailored to help me speak in school. Furthermore, if my parents were worried about me not feeling academically engaged enough, the district would enroll me in the gifted program at Woodland at the same time.

Mother and father were satisfied with this solution. All that was left was to tell me about

the idea. One afternoon, towards the end of the school year, the three of us sat around our dinner table for a “family meeting.” They told me the plan and the reasoning behind it. “We and your teachers all think this will help you a lot,” they said. “But we know you might feel nervous about leaving Worcester. What do you think, Helen? Will you be okay?”

In truth, I was uncertain. Although I had struggled a lot at Worcester, I had still managed to make some good friends, and I hated to leave them. I worried that if I went to a new school, I would have to deal with teachers and classmates misunderstanding me all over again. It was hard enough being “the girl who doesn't talk.” It was probably even harder to be “the new girl who doesn't talk.” And yet, I had nothing else to pin my hopes on. Maybe a fresh setting would be the key I needed to unlock my voice from its box.

~\*~

The flowers of spring faded away, and the harsh light and heat of summer settled over the land. It was June on the last day of second grade, and I was watching the clock in Mrs. Cain's room from my desk, waiting for the hands to point to the time when I would hear my very last Worcester bell. There was a pang in one half of my heart, a pang that flared up when I gave farewell hugs to the few kids I'd befriended in my two years here. But the other half of my heart felt light and jumpy, as if it were a bird flapping its wings, ready to break free from a cage it had been trapped inside for far too long.

*Doooooooooooo!*

At the sound of the bell, all of the kids in the class leaped from their seats, threw on their backpacks, and rushed out of the classroom and into the halls. Laughter, cheers, and goodbyes filled the air, and as I walked out of Mrs. Cain's room for the last time, I heard teachers calling to their students, “See you next year! Have a good summer!”

But there would be no next year for me at Worcester. Unsure of when I'd ever see this place again, I walked very slowly, absorbing every sound and sight. There was the window overlooking the green, grassy expanse we had field day on. There was the art room, one of my favorite places, with posters of Dalis and Van Goghs and Monets hanging up inside. Down the stairs was Mrs. Buck's room, with Mrs. Buck standing right by the door, smiling at the departing students, me included. Past her was the wall of green slips, the certificates given to exceptional kids who were generous and kind to others. Then there was Mrs. Broadham's office, which still left a bad taste in my mouth. There was the main office too, where our principle, Dr. Greene, made announcements over the school speakers in his booming, jovial voice. There was the nurse's office, where I went whenever I got a nosebleed, and the nurse would give me a Tic-Tac each time because she was so nice. There was our big library with the cushy bean bags that I loved melting into with a good book.

Finally, at the front of the school, there were the glass doors I had walked through on my very first day. The yellow school buses were all lined up outside, ready to take everyone home. Moving along with the crowd of students, I stepped past the doors for the last time. Before I boarded my bus, I took one more glance at my school over my shoulder. The building seemed to glow underneath the June sun, and the American flag in front of it fluttered gently on its pole. *I'll miss you*, I thought, as I stared at the flag. I imagined it was sending me off—red, white, and blue waving goodbye.

## Chapter 6

### Hidden Feelings

*“In my young adulthood...one of my profoundest worries was that I would never marry or have a family of my own because I was suffering from something I was so ashamed of—something which, I believed, nobody could accept me for.” - Carl Sutton, Selective Mutism in Our Own*

#### *Words*

“I broke up with him,” a girl complained to her friend loudly in our middle school’s halls. “Because he stopped telling me that he loved me.” A thirteen-year-old me, walking past this girl, took a moment to wonder. Did people really put that much emphasis on *saying* “I love you”?

Dating seemed like it was all the rage in middle school. I guess that’s not a surprise; those years are the ones when all the hormones start flaring up, drawing teenagers towards each other. Everywhere around me, I could see couples holding hands, chatting together outside of classrooms, and sometimes even kissing in the stairwells. And every time I saw these things, they felt very foreign to me because I was convinced I would never be able to experience that kind of bond due to my selective mutism. Sure, I still fell in love with people, but I kept my middle school crushes to myself. I couldn’t use my voice to ask anyone out or tell them that I loved them or cared about them. Besides, what guy would ever want to date a girl who couldn’t talk? I was weird, not cute. I was someone to be made fun of and gossiped about, not someone to be attracted to.

Thus, whenever I developed a crush on someone, I would never give any indication that I

liked them, not even non-verbal ones. I would only watch them from afar, daydreaming about what it would be like to have their arms wrapped around me. I suppose it's a sappy, generic mental image, but back then, I wanted nothing more than to live a “generic” life without selective mutism. To me, having a boyfriend would have made me feel a tiny bit more normal.

There was one time where I felt closer to achieving that goal. In seventh grade, I started to like one of the boys in my class. His appearance fit the stereotype of a jock; he was at least a head taller than me, he had a strong frame from playing soccer, and his brow looked a bit like a gorilla's. Unlike the stereotypical jock, however, he wasn't an utter idiot, nor was he mean or arrogant. He shared most of my honors courses, and he actually took a more advanced math class than I did. If he did say or do something silly, it was more endearingly dopey than stupid, like the time he got into a debate with our (even more muscular) reading teacher over what would happen to an ant if it leaped off the Empire State Building. He never seemed bothered by my mutism, and he treated me like he would any other classmate. This was what drew me to him—though of course, I was fond of his looks as well.

During the classes we shared, I'd furtively sneak glances at him while the teacher lectured. In our reading class, I even got lucky enough to have an assigned seat in front of him, which meant I could go over worksheets with him and lend him pencils (he forgot writing utensils an awful lot). I wasn't sure if he realized I liked him, but we were at least good acquaintances who could work together without problems. It wasn't until I began receiving official treatment for my selective mutism that I considered trying to make my feelings more known to him.

One goal of my treatment was to steadily get me speaking with more of my peers in hopes that I would eventually be able to talk in front of an entire class. It was impossible for me

to achieve this in a normal classroom setting, as the number of students was too great and made my voice lock up in nervousness. My parents, counselors, teachers, and I thus decided the best method would be to schedule me for individual “talking sessions” with each student I wanted to speak to. These sessions would be held in my guidance counselor’s office, a quiet, private location where I was guaranteed not to be disturbed. At that point, I was already verbal with my counselor, so her duty was to lead me through the same process I used to start talking to her with the other student.

I was asked to make a list of people I wanted to work with and included my crush in it. My special education teacher prepared a letter explaining the situation and sent it to everyone on the list, in order to obtain their parents’ consent. The gist of it read:

*“...I have been working with a student from your son or daughter’s section named Helen Tang. Helen is a student who is gifted. Helen is also a student with Selective Mutism...a childhood anxiety disorder characterized by a child’s inability to speak in various social settings. These children are able to speak at home and in settings where they are comfortable, secure, and relaxed... School is usually the most difficult place for children with Selective Mutism to be.*

*In order for Helen to feel comfortable and begin to communicate in the classroom she has to feel comfortable communicating with everyone in the classroom... Helen selected your child as a student she would like to begin to talk with. Your child will go through a few talking exercises with Helen called the Ritual Sound Chart. This will be done at the beginning of a selected class period. It will take no longer than 3-5 minutes. Your child will not be pulled out of class or miss any class time...*

*...Selective Mutism is like any other childhood fear whether it is a fear of the dark, spiders, loud noises, or being alone. Just like we would want your child to overcome their fear,*

*we want Helen to overcome her fear. Your child is being given a unique opportunity to make a lasting impact for the better for their fellow peer.*

*With your permission we would like to begin having your child work with Helen on Tuesday May 27..."*

I was worried that his parents would not approve; the meetings had to be done during class time, and I wondered if his family would want him to prioritize his studies over me, much like how my own parents always said they wanted me to concentrate on school over dating. I was worried that the guy himself might find the invitation strange and decline. Thankfully, neither of those two outcomes happened. My counselor informed me that his parents had agreed to let him work with me, and I felt a tingle of excitement run through my entire body as my heart went into a staccato rhythm.

On the day of the first meeting, I was so ecstatic that I could barely look at my crush's face as we headed to my counselor's office together. It was a silent walk, which would perhaps feel awkward to other girls, but I was too occupied with thinking about how our relationship could change for the better once I started talking to him. When we got there, we settled down on chairs in a triangle formation with my counselor, who explained to him the process we'd be using. It was called the Ritual Sound Chart, designed by the therapist I was seeing outside of school, and it included a series of steps designed to gradually build up my confidence in talking. The first was making simple sounds; the boy would ask me a set of pre-determined yes or no questions, to which I'd respond "ssss" for yes or "nnnn" for no. After I became comfortable with that, I'd move on to answering the questions by whispering full words, "yes" or "no." Following that was replying to a set of open ended questions by using other words, such as "what is your favorite color?" (to which I'd say blue). The last step was saying fully fledged sentences, the

gateway to being able to hold actual conversations.

We would meet to work on the chart once per week. Although I was always eager to see him, the task of starting to speak was still nerve wracking. My first “ssss” and “nnnn” sounds were very quiet, and I found that I could never really meet his gaze while answering his questions, as I thought it would betray my nervousness even more. He didn't seem to care. He was always very patient no matter how long I took, watching me with steady eyes, and he never showed any signs that he found the process bothersome.

We reached a point where I could deviate from the pre-established questions of the Sound Chart and give short answers to anything he asked. What was my favorite food (“I don't know.”)? What was a place I really wanted to travel to (“Japan.”)? After these meetings, I always found giddy on the inside, warm and jittery and radiating sunshine. We weren't exactly having conversations, but it felt like we were at least getting to know each other more as individuals.

Yet, I still couldn't muster the courage to say that I liked him. Every time I thought about doing it, waves of embarrassment would crash down on me and fill my throat, drowning those three special words. The days went by. Soon, summer break was upon us, and I did not see him at all during that time.

The next year, he wasn't in any of my classes. All the progress I had made with talking to him was rendered moot, as I couldn't put it into practice. To top off, I heard rumors in the hallway that he had asked out another girl. With a heavy heart, I gave up on my endeavor, thinking again that I'd always be doomed, watching on the sidelines.

## Chapter 7

### Survivor

*“Can a person outgrow it? Many people will tell you they have done just that. There are ways to cope. But I think, for the majority, including myself, it will always be there.” - Kimberly Gerry-*

*Tucker, Selective Mutism in Our Own Words*

I have, on occasion, been called a “survivor” of selective mutism. Whenever I hear this term, I disagree with it. “Survivor” implies having outlasted some kind of event, and I can see why some might call me that since my SM has been mostly treated. But admittedly, it hasn't been purged completely from my life.

Despite no longer having problems talking in public, at school, or to new people, there is still a little bit of SM left in me. It crawls out of its sinister den whenever I'm confronted with Chinese family friends or relatives other than my parents and sister, including my mother's parents, the ones who cared for me before grade school. This happens more often than I'd like. Every year, I inevitably end up at some kind of Thanksgiving feast, Christmas party, or reunion where I end up in a swarm of my parents' raucous Asian colleagues and classmates. Mom and dad will bring me to the unfamiliar ones and prompt me to introduce myself, but I can never do it. The old nervousness bubbles up in my gut, and my throat clenches shut as if I have regressed to my severely anxious school days. I can only meekly smile as I wait for my parents to laugh it off and excuse me by saying I'm not much of a talker. Once I'm off the hook, I scurry to the quietest spot I can find, which can be difficult when the entire house is thrumming with the

sound of Mandarin and occasionally earsplitting karaoke. When the spot is obtained, I take out my laptop so I can avoid social situations by appearing immersed in some important task, leaving only when it is time to eat.

This phenomenon has always been difficult for me to explain. I have Chinese American friends that I do talk to (in English), and the individuals I don't talk to are not distrustful. I can only come up with two reasons as to why I behave this way. First, even though my native language was Chinese, my fluency in English has far surpassed my fluency in Chinese over the years, making English my preferred language in all situations. I haven't formally studied Chinese since middle school, and since I had selective mutism, I couldn't even participate in oral exercises while taking Chinese classes. As a result, my skills in that language have diminished to an elementary school level, and when it comes to conversing with people who prefer to or only speak Chinese, I always feel awkward. I constantly question if I'm using the right phrase and second guess my pronunciation. The pressure of trying to have a fluent conversation in Chinese is so great that I suspect it triggers my mutism. In a way, it parallels what happened to me after Brett made fun of my slight accent; I lost confidence in my ability to speak English and as a result stopped using it in public.

The second reason is the awkwardness of expectations. When you've had an easily observable condition like SM for so long, people expecting you not to speak becomes the norm. When that's the norm, you worry people will get excitable once you finally do speak, yelling, "Oh my god, she talked!". Perhaps they will crowd around you. Perhaps they will smother you with praise. This only serves to heighten your anxiety because you just want to be a normal person able to do a normal thing. You don't want to be singled out and given an uncomfortable amount of attention since you've already gotten quite enough of that as "the kid who doesn't

talk.” Since my relatives in China and my parents' Chinese friends are some of the people who are most used to my mutism, as well as some of the people who most want to hear me speak, I feel uneasy about talking to them.

It seems I'm not the only one with this concern. Carl Sutton, a researcher who had SM from ages 14 to 23, writes, “Speaking...would feel like being a jack-in-the-box and hollering 'surprise' to everyone whose presence triggered muteness in the first place.”<sup>1</sup> The mother of a selectively mute child named James says that when James read a book aloud in class for the first time, it helped that “the teacher did remember not to make a great fuss about it.”<sup>2</sup> Because this fear is so widespread among children with SM, it is a common recommendation in treatment methods not to react strongly to a child speaking aloud for the first time. Act normal and do not make it seem like a big deal, even if you want to cheer in joy for the child.

~\*~

The last time I visited China was during the summer of 2013, well after my leaps and bounds in overcoming selective mutism at school. My grandfather on my father's side, my *ye ye*, was dying of prostate cancer. Though he kept up a good attitude, laughing and rambling as he always did, the toll on his body was clear. He slept a lot. Sometimes there was blood in the toilet after he used the bathroom. He couldn't hold his urine, either. One time we were taking a taxi to go to a restaurant, and *ye ye* had used the restroom before we left, but in the middle of the highway, he had to use it again after roughly twenty minutes. We stopped the taxi just so he could pee.

My father and I had discussed trying to speak to my grandfather before we went to China. “*Ye ye* doesn't have much longer,” he said. “You probably won't be able to see him anymore after

---

1 Sutton and Forrester 21

2 Cline and Baldwin 3

this trip. In his entire life, *ye ye* has never heard you say a single word to him. Please speak to him, Helen. It would make him very happy.”

I could tell my father's expression was somber through his tone, even though I couldn't bear to look at him while he spoke. I knew the urgency of the situation perfectly well. But the weight of the task, the significance it carried, left me feeling frozen, utterly paralyzed. I couldn't turn to face my father. I couldn't face the duty he gave me.

At some point in China we ended up in a hotel room, where I was on my laptop as usual, trying to drown out the shrill sound of my aunts bickering about the Chinese housing market behind me. My dad came over to me with *ye ye* and asked me if I could show my grandfather some pictures from school and our other vacations. I obliged, opening up my photos on my computer and slowly going through each one. At times *ye ye* wondered what he was looking at. I wanted to elaborate, but I had neither the vocabulary to explain nor the ability to dispel the tension already growing in my throat.

Then came the moment I had been dreading. “Helen,” my dad said, leaning in close, “*jiao ye ye yi xia.*”

Say grandfather. All I had to do was say “*ye ye.*” Two of the same Chinese character, put together to mean my father's father, a man who I should have been close with, a man whose unconditional love I should have been able to reciprocate by giving him the simple pleasure of hearing my voice. Time seemed to slow. My body felt like stone. Again, my eyes could not meet anyone else's, refusing to budge from my laptop screen. I clicked through the photos again in a vain effort to quell the anxiety rising within me.

My dad repeated his command, his voice sterner. My aunts' chattering receded further and further into the distance. After a few minutes passed, it became apparent that I could not fulfill

my duty. I sensed an aura of disappointment emanating from my father. I became overwhelmed with feelings of incompetence, powerlessness, and guilt. And yet, *ye ye* himself did not seem to mind. *"It's all right,"* he chuckled in Mandarin. *"I understand."*

*Ye ye* passed away not too long after we returned to the United States. I felt numb when I first heard the news, not even able to cry. But three years later, when my father recounted this moment while we were dining at TGI Fridays, I wept. My *ye ye* was a good man. I regretted not having the strength to give him what he deserved.

~\*~

I am not a survivor because my SM lingers. Even if I were to eliminate my SM completely, I would still have the scars from the ordeal. Thinking of doing interviews makes my pulse and breathing rate spike; it's sometimes so bad that I suffer mental breakdowns. I still dislike hearing my voice in video tapes and recordings, and I occasionally find myself terrible at keeping conversations going in person. Most significantly, I still haven't been able to establish close relationships with anyone in my extended family. Without the power to talk to them, they feel like mere acquaintances, as much as they might love me.

If I am not a survivor, what am I? My sister has proposed the term "experiencer," which feels odd on the tongue but seems to fit better. Experience is always continuing. My experiences from the past shape the me of now, and my experiences in the present will shape the me of the future. In that sense, I'm never really finished with selective mutism. It will always be a part of my identity, and I accept that.

## BIBLIOGRAPHY

- "Autism Spectrum Disorder." *Centers for Disease Control and Prevention*. U.S. Department of Health and Human Services, 11 July 2016. Web. 17 Mar. 2017.
- Cline, Tony, and Sylvia Baldwin. *Selective Mutism in Children*. 2nd ed. London: Whurr, 2004. Print.
- Dickstein, Steven G., MD. "Can My Child Have Both Autism and Selective Mutism, and Be Treated for Both?" *Child Mind*. Child Mind Institute, n.d. Web. 3 Apr. 2017.
- Hua, Alexandra, and Nili Major. "Selective Mutism." *Current Opinion in Pediatrics* 28.1 (2016): 114-20. *Ovid*. Web. 19 Mar. 2017.
- Omdal, Heidi. "Can Adults Who Have Recovered from Selective Mutism in Childhood and Adolescence Tell Us Anything about the Nature of the Condition and/or Recovery from It?" *European Journal of Special Needs Education* 22.3 (2007): 237-53. *Taylor & Francis Online*. Web. 26 Feb. 2016.
- Schwartz, Richard H., MD, and Elisa Shipon-Blum, DO. "'Shy' Child? Don't Overlook Selective Mutism." *Contemporary Pediatrics* 22.7 (2005): n. pag. Print.
- "Selective Mutism." *GoodTherapy.org*. GoodTherapy.org, 21 Aug. 2015. Web. 19 Mar. 2017.
- Shipon-Blum, Elisa. *Easing School Jitters for the Selectively Mute Child*. 2nd ed. Philadelphia: Selective Mutism Anxiety Research and Treatment Center, 2003. Print.
- Shipon-Blum, Elisa. "When the Words Just Won't Come Out": Understanding Selective Mutism." *Selective Mutism Group*. Selective Mutism Group, n.d. Web. 29 Nov. 2016.
- Shipon-Blum, Elisa. "Understanding Selective Mutism: A Guide to helping our teachers understand." *Selective Mutism Group*. Selective Mutism Group, n.d. Web. 29 Nov. 2016.

Sutton, Carl, and Cheryl Forrester. *Selective Mutism in Our Own Words*. London: Jessica Kingsley, 2016. Print.

Wong, Priscilla, MD. "SELECTIVE MUTISM: A Review of Etiology, Comorbidities, and Treatment." *Psychiatry* 7.3 (2010): 23-31. *PubMed Central*. Web. 19 Mar. 2017.

Zalla, Tiziana, and Marco Sperduti. "The Amygdala and the Relevance Detection Theory of Autism: An Evolutionary Perspective." *Frontiers in Human Neuroscience* 7 (2013): 1-15. *PubMed Central*. Web. 20 Mar. 2017.

## ACADEMIC VITA

Helen Tang  
hxt5075@gmail.com

### **Education:**

**The Pennsylvania State University, University Park**  
College of the Liberal Arts, Schreyer Honors College  
Bachelor of Arts in English  
Bioethics and Medical Humanities Minor

### **Thesis:**

*Wordless: Living with Selective Mutism*  
Overseen by Elizabeth Kadetsky

### **Work Experience:**

**Part Time Retail Worker, Brooks Brothers**  
**Limerick, PA // July 2015 - Aug 2015**

- Assisted customers with selecting products throughout peak hours.

**Tutor (Symbolic Logic), Penn State Learning**  
**University Park, PA // Aug 2014 - Dec 2015**

- Helped over twenty individuals understand course material and improve their grades.

### **Volunteer Work:**

**Secretary, The Penn State Super Smash Brothers Club**  
**University Park, PA // Aug 2015 – May 2017**

- Created art and graphics for club social media pages and fundraisers.
- Assisted with organizing, advertising, and running club tournaments.

**Secretary, The Penn State Video Game Club**  
**University Park, PA // Aug 2015 – May 2017**

- Cooperated with other officers to plan and run events.
- Regularly informed club members of upcoming activities through e-mail and Facebook.

**Moderator, The Lands of Evelon**  
**landsofevelon.com // Dec 2014 – Current**

- Cooperated with other staff to develop enjoyable activities for over 50 active forum users.
- Created and edited over 200 graphics and artworks for the website.
- Enforced community rules to maintain a safe, fair, and pleasant experience for all users.
- Completed work under tight time constraints.
- Entrusted with updating important records regularly.

**Member, Springfield FTK**  
**University Park, PA // Aug 2013 – Aug 2016**

- Employed various fundraising strategies to help raise over \$200,000 per year for pediatric cancer research and treatments.

- Provided emotional support for families affected by pediatric cancers.

**Honors/Awards:**

- Dean's List // Fall 2013 – Fall 2016
- Showcased in the Penn State School of Visual Arts “A SoVA Collective”