

# *A Raging Silence*

No One Understands



*By Jeff Foreman*

*A RAGING SILENCE*  
**No One Understands**

**NO ONE  
UNDERSTANDS**

Living in a world and trying to fit in,  
but no one understands.  
Trying to get through life the best way I can,  
but no one understands.

If it were easy to make friends, have a job  
get married or just have a life, I would  
But no one understands.

Trying to get along with people  
The best way I know how,  
But no one understands.  
Feel like dying now,  
But no one understands.

Why don't you look at me instead?  
Of judging me???

My feelings are jumbled  
But no one understands.

Acting out in ways that are inappropriate  
But no one understands.

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### **ASPERGER SYNDROME**

Asperger Syndrome is a developmental disorder falling within the autistic spectrum affecting social interaction verbal and non verbal communication and a reluctance to accept change, inflexibility of thought and to have a very narrow area of interest which consumes the individual. There is a range of severity of symptoms and not every child shows all or the same symptoms. The very mildly affected child often goes undiagnosed and may just appear odd or eccentric.

Asperger Syndrome is much more common than Autism but it is still a rare condition and few people, including professionals will know about it much less have experience with it. It seems to be more common in boys than girls. Those with the syndrome find making friends very difficult, because they do not understand the subtle clues needed to do so. The language they use can be in an odd way, and they frequently take literal meanings from what they have read or heard. Because of their rigidity, they do better with routines and structure in their environment. Change is very difficult for them. Negative behaviors, which often accompany Asperger Syndrome, often stem from the difficulty in communicating their frustrations and anxieties.

There continues to be a debate as to whether Autism and Asperger are the same, but for diagnostic purposes Asperger is listed under the umbrella of PDD (Pervasive Developmental Disorder) in the DSM-IV used by physicians. Uta Frith an expert on Autism refers to Asperger as “having a dash of Autism”.

Having lived with this syndrome I have watched Jeff go through the stages of Autism to Asperger Syndrome and I am a believer that the two are much the same, if not the same. I really do not see the difference.

The main areas affected by Asperger Syndrome are:

- Social Interaction
- Communication
- Narrow margin of interests
- Rigidity and Inflexibility

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### **INTRODUCTION**

#### **AUTISM ASPERGER'S SYNDROME**

It happened in a hospital, on the side of Mount Royal in Montreal, Canada at five fifty-five a.m. in the month of May 1977. My mom gave birth to a baby boy and my parents named me Jeff. My name is Jeff, I am nineteen years old, I have reddish-brown hair, but I like to call it brown because I prefer my hair to be brown. I have brown eyes, I'm six one and a half and I have **AUTISM**.

A few years ago, I wondered what I was like when I was a baby. When I asked my mom, she told me some things I wanted to know, and at meetings that I went to later, I heard stories as well.

One of the stories took me back to when I lived my first three months. As soon as I was born, my mom and dad were very busy with me. I cried every single day and every single night, and my mom and dad never got any rest. If my mom did get rest, it was only a few hours a night. One day my mom decided to time me to see just how long my crying lasted. After 19 long hours that must have felt like forever to my mom, I finally stopped. This was an everyday routine for us. My mom has a **theory** based on the fact that some autistic people have very **acute** hearing. Given that most babies sleep through normal household noises, she believes that those household noises were terrifyingly loud to me, and made me scream in terror. When she would put me down for a nap, if I did go to sleep, and she would use the vacuum cleaner or do other things in the house, I would end up screaming really hard, as if in hysterics.

Night after night when she would in fact get me to sleep, as soon as she got to her bedroom, she heard me crying again. She believes that because my dad read the newspaper in bed at night, that I would hear him turning the pages and I would wake up again, terrified. She still believes that a big part of the problem was my acutely sensitive hearing.

What ever my mom did, it would never put me to sleep. She would put me in a baby carriage and take me for walks or one night Mom and Dad were so desperate, they put me in the car and they drove all the way to Ontario, thinking that the motion of the car would put me to sleep. I cried and screamed all the way. The doctor's answer to the situation was that I had colic.

If the house was totally quiet, I may settle a little, but if anybody rang the doorbell, or a vehicle went by the house, or other outside noises would set me off again and I would scream hysterically. My screaming even bothered the neighbors who lived beside us and behind our house.

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My mother couldn't find anybody to baby-sit with me because they couldn't stand the screaming. When I was four months old, my mom called her friend who agreed to stay with me while she went to my grandfather's funeral. When my mom returned, her friend asked her how she could stand the constant screaming, and she said that there was no way that she would be able to stand it all the time like my mom had to.

Another characteristic of autism is no eye contact. I have pictures that were taken of me where I just stared at the camera or off to someplace else with no expression whatsoever. In some of these I was only six months old, and as you will see in childhood pictures, the absence of eye contact continued for several years.

There are a lot more things than those, like when I had a little toy. The toy was a little bird named Tweety, which didn't last long because when my mom gave it to me, I destroyed it. So my mom gave me one like it only it was Sylvester the Cat, which I also destroyed in the same way. I banged things and in banging the toys over and over again, they eventually broke into pieces. She says that people with **autism** many times have odd behaviors like constantly twirling things, spinning things, tapping things, and it seemed to her that I got lost in banging things. As I got older, it would be the eating utensils at the table. Even as a teenager, my mom would tell me to put down a spoon that I was banging. I would put it down, but immediately pick up the fork and start banging it.

When I was six months old, I smiled at my Mom purposefully for the first time. She was so happy that I had done something normal for once that she called up the friend who had stayed with me during the funeral, to share the excitement.

Around the same time, I started choking for no apparent reason and my mom found it disturbing. She called the doctor who said there was nothing wrong with me and that because I was her first child, she was just nervous. About five and a half years later, she found out that the choking was related to seizure activity that I had.

By the time that I was ten months old, Mom was so exhausted that she called the hospital and told them that she just couldn't take it anymore. They admitted me for five days to see if there was something wrong with me. The doctors did a lot of tests, and they couldn't find anything wrong. They sent my mom home to rest, told my dad to take her out alone occasionally, and ended up telling her that because I was her first child, she was just nervous. Mom and Dad took me home after the five days and nothing had changed. People from the hospital came to the house to teach my mom how to let me cry.

The evening of my first birthday, my parents and my grandmother were there. After supper my mom brought in my birthday cake with a burning candle in it. As they sang *Happy Birthday* to me, I just suddenly looked very sad and started to cry, not the kind of crying I usually did, but a heartbroken cry, as my mother described it. I seemed to be afraid of the cake and/or the singing, or was it the emotion of the moment that was

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involved? They removed the cake and stopped singing before I would calm down. My mom felt very bad and didn't understand my reaction to something that usually makes a child smile. It broke her heart, after the troublesome year of my life and now this, this being an event that is suppose to so much fun and exciting turned into a sad and worrisome event. My mom didn't get to see me play in the chocolate frosting and smear it all over my face.

We moved to an apartment when I was 13 months old, and at this point, I was walking. One day my mom's friend came over with her child who was a little bit older than me. She held her child for a while and when I went out of the room, she put him on the floor. He followed me into the bedroom and when he came to the door, I started screaming hysterically. My mom said it seemed like his presence there frightened me because when the other child's mother took him away from the door, I stopped crying. She said she thought it was strange that I should cry like that in that kind of situation and in that manner.

When I was a little older, one warm, sunny day my mom decided to take me to the park. When we arrived, no one was there. I was playing in the park and wanted to go to the slide. My mom watched me and helped me so I could go down the slide. At one point, when I got to the top of the ladder, I looked around and saw a child coming toward me. I stood there and started crying, again hysterically, and my mom had to ask the man to remove his child from the slide while she got me down. As soon as he took the child away from the slide, I stopped screaming. My mom was very embarrassed, but also very concerned about why I was acting the way I did.

That same day in the afternoon my mom called the doctor. The doctor responded by saying that until I got a bit older, I would be crying like this, that that was who I was. She also said when I turned three or four years of age, that my mom could sit me down and tell me that the crying was inappropriate and that I should stop. My mom was furious because she knew that something was definitely wrong and the doctor acted as if my mom was crazy.

Shortly after, we were at church and, as usual, I was crying for no apparent reason. My sister who heard me all the time, started to imitate me. She began crying, too, for no apparent reason. My mom's friend said that she would talk to her child's doctor about the situation with me, and explain that my mom couldn't seem to get my doctor to realize how serious the problem was. She would ask if he would see me and give a second opinion.

He advised my mom to again phone my doctor and ask her for a referral to the Day Treatment Center at the Montreal Children's Hospital. Many long weeks later, Dr. Alexandra Roussos at the center saw us on an emergency basis. She observed me for one hour while she spoke with my parents. As she watched, she saw that my only play was that I took the cars and put them in a line. She noted that I **didn't have imagination** as to what I should do with the cars, but only line them up, and then at times, I would

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change the cars around, but always in the straight line. I did this without making a sound, no pretend car noises. This was a concern to her and she told my parents that this indicated a very real problem with me and that I would start treatment in the center immediately, along with some medical tests. They checked my hearing and speech. My hearing was O.K. but they had me seen by a speech therapist that put me in a speech group, however, I didn't talk to her. She told my mom that the way I sat and the fact that I had so profuse drooling indicated that I had some sort of neurological problem.

I was also in a placed in a playgroup to help me learn how to play with and as other children play. During this group, the doctor and my mom would observe me through a one-way mirror/window. The doctor was concerned about the way I was in my own little world. I sat away from the rest of the group, and seemed content and happy in that world. She told my mom it was as if there was a bubble around me. My mom has since thought that Dr. Roussos suspected that I had autism, but hesitated to put a label on me too soon.

After that, I was at the hospital for treatment of some kind, every day of the week, until the fall when they recommended that I should probably go to the Dorval Day Care where being with other children could have an influence on me, hopefully encouraging me to talk and pick up the 'normal' play of other children. If it made a difference, it was very little.

During the waking hours, my mom could not get me to stay in a room in the house away from her, so she couldn't get work and chores done in the house. She noticed that I seemed to enjoy music and she bought me a children's record player. That did it!! I loved music and would stay occupied and by myself and play my records over and over again for a long time.

After three years, I did not begin to talk and I didn't learn to play with the other kids. I did not learn to go to the bathroom either. Everyday my mom had a fight with me to get me inside the Day Care and she soon learned to just pick me up and take me. Even after I was finished there and went onto regular school, and my brother and sister went to the Day Care, I would fight to not have to go in for special events.

After my mom would get me there, I would stay close to my teachers, but never said a word to them. They always had to physically take me to each activity and try to make me play with the other kids. I would never do anything on my own or play with imagination like the other kids.

Moving ahead seven, eight, or nine years, my old problems had disappeared but new problems came in and took their place. Anything that made any type of noise or people hanging around me did not seem to bother me so much, however certain shrill or high-pitched sounds that don't bother people still hurt my ears. When kids would invite me to their birthday party, I wouldn't go because I was very shy. My mom and dad would

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drive me to the house but I would not get out of the car. Now, these days, I am going and it is fun.

In my family, TV used to be a big problem. When my brother, Matthew and my sister, Amber, watched TV I would go and turn the TV to the channel that I wanted to watch, and this happened all the time. Everybody was very upset and I was even more upset because I never got what I wanted anyway. My mom would take me out of the room or turn off the TV She tried to get me to share so we could all get a chance to watch some of what we liked. I would then become totally out of control and my mom would have to hold me until I calmed down, which could be hours. The people at the hospital taught my mom how to do this so I wouldn't hurt myself or other people. She was to do this anytime when I seemed to be getting out of control.

I didn't do sports and I couldn't make friends because I'm afraid and shy and so I used to stay home a lot.

When I talk to someone they have to explain it in a certain way so I will understand. When I talk, I mostly don't make sense but now and then I do. When I am into a fight with one of my family members, they agree with me to avoid a fight, but it doesn't work, it just gets me mad. I do like getting teased, but when my brother teases me he doesn't do it in a nice way and he also jokes about things that are serious, and I don't like that my mom used to say that I was unique. I was sixteen years old when we found out what I had. Finally, my mom put an article in the newspaper. One day, the phone rang and someone called about Asperger's Syndrome. More and more people called us about it. Now my mom and dad are holding a meeting about once every month for people who are involved with somebody having Asperger's Syndrome. I think there are about twenty-five people who attend the meetings regularly. Now I know that I am not unique. Everybody who has autism is different because I know someone who has autism and we have the same situations except for one. People pick on her and people ignore me and there is another difference, too. In some cases it is mild and in others it is severe. I'm mild in that I actually look normal, but I'm not. Sometimes I wish that I were dead because this autism causes me a lot of trouble and I keep on trying to be normal, but I can't.

There are reasons why I am alive. First because I am a Christian, and second, because I am afraid to die and third, when I see other people who have different problems like people in wheelchairs, I know that I am fortunate enough to walk. When I see people like that I know I'm more fortunate than they, but I still feel bad for them. People who ignore or pick on people who have autism shouldn't. Instead you should try to get to know them. The reason why I'm saying this is because it's not the way the person acts or what he/she looks like, but how they feel. People should try to get to know them, because it's not their fault that they are autistic. If you get to know them you might be surprised. They probably want to die too, but I don't know. I do know one thing; they are human and have feelings, too. Sometimes I run into situations like that, too, and I talk to them and I find them pretty cool, and I like them. No matter how long or rough it

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is for me to make friends, I will never give up because it's my dream to have friends and a girlfriend and maybe when I'm older I would like to get married.

The reason why I am writing this book is because, not only do I want friends, but also my main reason is to help other families that have the same situation as mine. **NO, you are not alone.**

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From Mom's Perspective:

There's nothing more exciting than to feel that first movement of the baby kicking inside your womb. Not only is your waistline becoming a little thicker, but also now the life inside you is a REALITY. You begin to collect the baby needs, you know, the crib, the changing table, and the endless dozens of "cute" little sleepers and shirts and little suits that your baby will look so cute in. Oh, and especially the one he/she will wear on that big moment, going home from the hospital.

Everything is great for three weeks, then again REALITY steps in. All the wonderful, delightful sounds of that cute little baby have turned life into a waking nightmare. He cries continually, day and night. He doesn't sleep, you get no sleep, and the neighbors get no sleep. The crying lasts for nineteen hours and all of that 'volunteer' help disappears. Days turn into weeks, weeks turn into months. The grandmother says, "don't let him get the six-week colic." No, Mom, I won't. How about four months? Or should I say a year?

Where did all of that volunteer help which was so graciously offered while you were pregnant, go? It's you, kid, you and your "wonderful, darling," baby. Yes, you love him with every breath you take, and you would do anything to help him, to make him more comfortable, but no matter what you try, it just doesn't work. You are so tired by now, and alone, that life which was suppose to be at it's best, is the worst possible that you can imagine. All of your friends have so much advise for you, "Get him on a schedule," "Don't be so uptight." "Relax." "Don't hold him so much." "You're a nurse, your baby shouldn't cry so much."

After 10 months of this bliss, and you are about to crack from fatigue and the sound of a baby crying constantly, you decide you had better get help because something terrible might happen. The emergency team of the local Children's Hospital immediately admit the baby to the hospital, and tell you to go home and get a good rest. "Don't come back until 9:00 a.m. at the earliest." You do as you're told and when you arrive at the hospital the next morning, the nurse meets you with a great big smile and says, "Are we glad you're here, he hasn't stopped crying at all." (Told you!!!) But who would believe a

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mother? After five days, the doctors politely tell you that they can't find a thing wrong with your lovely baby, so, "Go home and get your husband to take you out more." They proceed to tell you that you are merely a nervous mother and need some help in how to deal with a new baby. You bet I'm a nervous mother by this time. Have you lived for ten months, caged with a roaring lion? One does tend to become a little nervous at this point. By the way, where did all the baby-sitters go?

Hundreds of hurdles, every day a new problem to solve, new challenges, new roadblocks, and twenty years later, I am probably the proudest and most thankful mother that ever lived. He, with the help of his heavenly Father, God, and his determination, has broken down many of those roadblocks, he has crossed hundreds of hurdles, and he has laid a path for others to follow. Yes, that seven and a half pound explosive, has become a pioneer in his world, a world which he wishes to share, and perhaps touch some lives that have or are experiencing similar adventures. No longer an explosive, but a warm, sociable, loving human being, whose goal in life is help other people like himself. He has no apparent outstanding abilities, he is not famous for special talents or achievements, but he is a young man who has suffered greatly, who has struggled, and who making a reality the impossible dream. He lives to show others who are going through the same things, that they are not alone and can do it, too. **REALITY**

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### **CHAPTER I**

#### **MY FAMILY AND I**

There are many kinds of families in the world. There are big, small, rich and poor families, but they are a family. Some people don't even have one. One of the most important things to make a family is LOVE. Every family is different except for one thing, and that thing is problems. Every family has problems especially mine.

My mom's name is Beverly. She is probably as tall as my shoulders. She has short, straight hair and blue eyes. She cares a lot. My mom cares about us so much that she works real hard and does a lot for us. She doesn't really get much for herself. She is very funny and serious. I like her when she is funny because I laugh at her jokes and that sort of thing and that makes me feel great. I also feel safe with her because she also understands me and what problems I have. That's why I have a very good relationship with her and a lot of trust. She is helping me to make friends in her own way. I don't know what I mean when I say helping in her own way because it's hard to explain. I really don't understand it myself, but she helps.

I have a sister, Amber. A lot of people say that she's pretty and that her hair is beautiful, and that they wish they could have it. Her eyes are blue. She's taller than my mom and smaller than I. Amber is nineteen months younger than me. My relationship with my sister is not as good as my relationship with my mom. Just like all siblings, we have our good times and bad times. Occasionally Amber will ask me if I would like to join her and her friends when they are out doing things like a movie or bowling, or to just play cards or hang out. Every now and then she teases me about my nickname. She calls me "Thumper" because I have big feet, and when I go down the stairs, I make a lot of noise. In response I call her "Hamburger" which is her nickname because it rhymes with her name.

When my sister is on her bad side, it would be wise to stay away. When she's in her bad mood, she gets bossy and touchy. Sometimes she stretches the truth or doesn't tell the whole story. Sometimes she over reacts. I use to think that it was because she was a girl. It seemed to me that my mom didn't much care, either. My dad definitely didn't care. Now that we've grown up, Amber and I understand each other a lot more. Amber knows that I have Asperger' and she helps me out in a lot of ways. She takes me out with her and her friends and includes me and encourages me to do better for myself.

My brother, Matthew, is almost as tall as me and has blue eyes as well. His hair is a reddish-brown color, the same as my sister's and mine. He is four years younger than me. He has no nickname either so I call him Matt or Matthew. My brother doesn't understand me nor accepts me for who I am at the present time; I have no relationship with Matt. He use to listen to music, which was not music but noise, and it was disturbing. It gave me a headache and there was a lot of swearing in it, but he thought it

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was cool. In some ways he is cool, but in others he isn't. I don't think he likes me too much because I'm not like him.

I don't understand computers, so when I asked him to write the instructions down, he yelled at me because I didn't understand, or if he did write them down he was not specific enough and then I didn't get to play much on the computer. It's because he didn't understand and was also impatient. When he started bugging me I would start to bug him a bit, too. Then he said he wouldn't set up the computer for me because I was bugging him. I don't think that was fair.

Sometimes Matthew was nice to me but not very often. My brother had an attitude and embarrassed me with his childish behavior. He doesn't do this anymore. No that Matt is older he helps me and does a lot for me. He seems to understand me better.

My dad's name is Ron. He has gray hair, brown eyes and he is taller than my mom and shorter than me. The nickname my brother gave him is 'Homer'. I call him 'Homer' for two reasons, because it is his n nickname and because I don't respect him or like him. I know that he sees me the way the world does. In a way he understands because he knows what Asperger's is, but he really doesn't show that he understands in his everyday behavior towards me. I had a paper route and when I went collecting, I asked him to help me and he did. He use to make models with me. Now I have a model that is half done and I don't know when it will be done. He doesn't seem interested in helping me anymore.

Now and then when we go out and he's with me, he embarrasses me. My brother, sister and myself don't feel that we have much freedom in the house. He's paranoid about the volume of our entertainment. He just doesn't want it low, he wants it so low that we can hardly hear it. We always have to keep the door closed even when he isn't around. I get upset when he does that; I can't have any freedom in the house. My mom allowed us to have our fun when we were teenagers and she didn't mind it.

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From Mom's Perspective

Having a disability within any family unit causes a strain on that particular family. Many and perhaps most times, families are able to work together to support the one with the disability, but many times destruction of the family unit occurs. Bottom line is when a disability exists in a family, the entire family is affected.

Initially the lifestyle that we had imagined and had been accustomed to changed drastically. The struggles began in an attempt to calm a screaming child and to find answers to what and why. We tried to maintain as normal a lifestyle as was possible. I

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couldn't get a baby-sitter because Jeff cried so much nobody wanted to stay with him. Therefore if we went out to dinner, I took Jeff along. He many times would cry all through the meal and when we tried to travel, I always found myself sitting aside to try to calm him. I went to church regularly, but always ended up sitting in the nursery the entire time.

Jeff's screaming frightened his younger brother. Matt grew to adulthood afraid of Jeff, and what he might do to him. Although Jeff never struck out in those younger days, his aggressive behavior frightened Matt. Even into young adulthood, Matt had difficulty coping with the fact that a person, who appeared to be like everybody else, could be so terrifying.

His sister, Amber on the other hand developed the mothering pattern and attempted to appease Jeff. She felt that anger on her part wouldn't be justified. As one could imagine, both of these reactions on the part of the siblings had a lasting affect on them and their own lifestyles. Both of them, many times, were known to comment on wishing they had a normal life. When they had friends over, Jeff's behavior terrified the friends, as he would become extremely upset and begin screaming. Jeff's behaviors ruined many birthdays for his brother and sisters.

The people at the hospital showed me how and when to hold Jeff to control his outbursts and to hopefully help him to learn to control them. There were times when I would hold him until he calmed down, which could be for two hours and then when he would calm down and I released him he frequently would go right back into the outburst and we would repeat the same process. He never learned from the procedure, it served only as a method of survival for himself and his siblings.

Throughout the years of not having a diagnosis on Jeff, not knowing what the problem was, too many hours were spent in the offices of social agencies, doctors, and all those people who were going to fix the problem. It was always mandatory that the siblings were there, no matter what they had to drop in their lives. Besides the times their friends were frightened away, there was little time left for making friends or pursuing their own interests. I always tried to see that they had their own lives, but the added pressure took its toll on them as well as myself.

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### **CHAPTER II**

#### **FEARS AND OTHER FEELINGS**

All of us have fears; some are stronger than others and some of them we can learn to control. I worry a lot because of my fears. I'm afraid of death, what happens in my future, and shots.

Death worries me the most. I wish I wouldn't grow older because that means that death is closer. I'm afraid because I can't imagine myself not breathing. That's why I can't stand small places like elevators because if they get stuck I can't get out to breathe. Until recently, I couldn't stand to sleep with my bedroom door closed. Now, I've learned to keep my door closed at night.

My fear of dying makes me afraid of touching chemicals, or being around them, I'm careful when fires are involved, and when I go into the kitchen, I am careful near the stove and the kitchen knives. I am afraid to go on a plane because of heights and that it might crash. This will lead to death, and I'm afraid to die.

One day my family went to Mount Royal in Montreal, and we stopped the car in a little parking lot. The mountain is in the center of the city and you can see a great part of the city from the top. After we got out of the car in the parking lot, we went to the railing and when we looked over, I felt a bit dizzy, and had to step back. I then saw my brother lean over the edge. I told him to step back because I was worried about him.

Another time I went somewhere with my sister and her friend. I didn't know exactly where we were, but we saw a very big clock and went in. We started up the stairs, but I stopped a little more than half way to the top. My sister and her friend went on up, and after a minute or two I went up very slowly on the next two flights of stairs. When I finally got to the top, my sister said I looked as white as a ghost.

I also am afraid of shots because I'm not sure if they are going to hurt or not. Sometimes they do hurt. I remember a time when I was five years old and I got a shot and it hurt. I remember the park across the street from the doctor's office and that it was a sunny day, but that didn't make the shot hurt less. Every time I had to go get a shot, my stomach would feel sick. Getting shots is only one reason that I don't trust or like doctors.

I'm also worried about what is going to happen in my future. I'm afraid of what I'm going to do after my mom and dad are gone. That is why one of my goals is for me to become independent, to learn how to take care of myself and do things for myself. This is really a fear that will never go away.

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### From Mom's Perspective

Exaggerated or unrealistic fears can be indicative of one who has Asperger's Syndrome. These fears were some of the first characteristics that Jeff displayed.

As an infant he was extremely afraid of household noises, which at the time I thought to be quite unusual. The sound of the turning of the newspaper pages would send him into uncontrollable hysterics. When I would vacuum, Jeff would scream hysterically. He loved trucks and cars, but when one would pull into the driveway, it would upset him terribly. I would talk with him and read to him repeatedly about cars and trucks and watching the activities of the garbage trucks through the windows of the house, but this fear did not subside for a very long time.

Jeff would go into hysterics when around another child of the same age. There was the day that a friend was visiting with her son who was close to Jeff's age, about thirteen months. As long as Jeff was across the room from the little boy, he was fine. However, at one point in the visit the little one came about five feet from him and Jeff again went into hysterics. The only thing that calmed him down was to take him to the other side of the room again. One day at the park, Jeff was the only child in the park and he wanted to go up on the sliding board. While he was going up the steps, a gentleman brought a little girl into the park and she came directly to the slide. When Jeff got to the top and looked around, upon seeing the little girl, he started to scream. I finally had to ask the man if he would take the child away from the slide until I could get Jeff down. With this, Jeff immediately quieted.

When Jeff had his first birthday, his grandmother whom was always very close to Jeff, came over, and we had the typical first birthday for him. It was just Grandma, Dad, and Mom, and when we sang happy birthday to Jeff, he began to cry sobbing as if his little heart would break. Was this some sort of fear that existed? Or was this involved with the emotional feelings that emerged with the singing of the birthday song? I would guess that we would never know.

As Jeff got older and was in school, he was invited to parties at the other children's homes. We would take Jeff, and although he was selectively mute at that time, Jeff would start to scream and yell and perhaps we would be able to get him to stay, by running out and leaving him if the host parent were able to help or we would return home with him. One never knew what to expect or how to deal with the situation.

Jeff also experienced some of the more common fears like dogs, insects, etc.

The doctors, and there were lots of them at the time, would give such advice as, "when he gets older we sit down with Jeff and explain to him that it wasn't normal to scream and

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cry like this and that it is time to stop. Or we were told to be firmer with him, or we, his parents, should get out more. The last bit of advice was a real laugh because there wasn't a baby-sitter alive who would sit with Jeff. Along with this bit of advice, I was told that I was just a nervous mother and I really should relax in order to help Jeff. Yes, by this time in our lives, I was truly a nervous mother, but it seemed that the professionals had gotten the cause and effect reversed.

To this point, Jeff was pre and early school age. Siblings and various attempts to determine the cause of Jeff's fears were of no help.

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## **No One Understands**

### **CHAPTER III**

#### **THE TROUBLE WITH TALKING**

For years I never talked and I couldn't do much like I can now. I was very frustrated, disappointed, and discouraged. I went to Terry Fox School for about five and a half years and I didn't have many friends at all. Because I didn't talk, I didn't do any work without one of my teachers pushing me all the way. I didn't go to the bathroom and I had to be pushed to even eat, just like doing my work. Sometime during those years my mom and I went to a room and played a game to try to get me to talk. My mom and my teachers were getting tired of it (after three unsuccessful months), so I had to go two days a week to the Jewish General Hospital. (The after school program). I hate hospitals but I had to go anyway. I was there for a while but no one could get me to talk. While I was there, I still didn't do anything like eating, working, and going to the bathroom. One day, one of the workers walked me to the washroom. I went in and just stood there, not using the toilet. I don't remember if the light was on or not, I just stood there. The worker forgot about me and when my dad came to pick me up later on, I wasn't around. The workers had all gone home, as well as the kids, and my dad had to have the hospital to search for me. When they phoned one of the workers at home, they realized that the last time anybody had seen me was when they had taken me to the washroom hours before. I was found in that washroom still standing there, just like I had been from the beginning. One time I was sitting at a table with other kids and one of them asked the worker why I wasn't talking. It really disturbed him that I wasn't talking.

One day, they got fed up with me there too and then I had to leave. They couldn't do anything for me, and I had to go to the Montreal Children's Hospital.

We had to go to a meeting first, and then my family and I had to wait for the decision, will I be admitted or not. When we went back in, I had butterflies in my stomach more than ever. We heard the decision and I was going to throw up or at least close to it. After the doctor showed us a place called 7D (the psychiatric unit of the hospital) we left.

On Monday, I started. My mom helped me pack up and brought me to the hospital. I was shown to my room and then I unpacked. I was to stay there from Monday to Friday and go home for the weekends. I would go on outings and on Wednesdays my mom and dad came to do something with me. I also went to a room where I was supposed to have my schooling. I began to stay in the hall. I guess it was because I was stubborn about going in. I never did like school. I had to let the teachers know that I was at the door by knocking but I never did that, so I never went in. I stood in the hall and refused to do what they wanted me to do. At first, they tried to get me to go into the room, but then they stopped that. I guess it took too much energy and while they were trying to get me into the room, the other kids were being ignored

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I was there for about out five months, but I still couldn't talk. They only kept kids on 7D for five months. After that you were discharged from the program and on to something else. The week before I was to leave, I had a good idea that might work, and it did. I was fed up with not talking, making people frustrated and mad, and I was frustrated and fed up with myself for not talking and it was time to draw the line on not talking. The line came pretty fast at this point.

My plan was that I would go into a quiet room with my mom and dad, and the nurse who worked with me throughout my hospital stay. Joyce, my nurse, asked me a question, and I nodded my head yes or no. Then after a w while, very softly, I said "yes" or "no." This was the beginning and soon I was talking with her. We then went out into the hall and I was able to talk there as well. This was so exciting to me and I began to talk louder and louder. My whole family and I went to get ice cream and I had to order my own. I told the lady that I wanted pralines and cream. We then went back. Everybody was thrilled, especially me, because I wanted to talk more than anybody in the world.

The same day that I started to talk, I started to eat and go to the bathroom by myself. On Friday, my mom and dad came to get me and we left the hospital for good.

My mom asked me why I couldn't talk. I was afraid to talk. I don't know why, I don't know what would have happened if I had talked. I was afraid of being embarrassed which would lead to more fear.

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From Mom's Perspective:

The elective mutism presented many problems for Jeff. Socializing and talking are things that most of us take for granted, but when the inability to perform these 'simple, natural tasks' is there, one soon realizes the magnitude that exists.

The professionals in areas of speech, social work, and education, were so perplexed over Jeff's muteness and continually tried to discover the reason for his being mute. I was handed articles and various sorts of advice on mutism, but nobody could find a solution. One teacher presented the idea that due to the fact that I, his mother, was from the United States, that the state of culture shock on myself was Jeff's reason for not talking. One professional actually came to the conclusion that there was a problem with the intimate relationship between my husband and myself and that was the reason for it. (Our sexual life had never even been mentioned before let alone the health of it)

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The severity of Jeff's inability to talk was unbelievably great. Although I experienced it constantly with him, I was also constantly amazed by the degree of control, which Jeff maintained. His barrier never came down at all. Those weeks that I went to school to try to get him to talk, we worked in a room with the door closed and locked. I played board games with him, read to him, bribed him with money and goodies, and did everything I could think of to get him to even mouth a word without sound and he could not do it. He was unable to even whisper in the car until we were completely and safely out of the school parking lot.

One time we had enrolled Jeff in a community program that consisted of play, crafts, outings and various activities. On one of the outings to a ski hill, Jeff and his worker went on the lift to the top of the hill. When they got to the top, the worker noticed a huge red swollen area on Jeff's leg, to discover that Jeff's leg had been caught in the safety rail the entire trip up the hill. Jeff had to have been in excruciating pain, but was unable to tell the worker or to ask for help.

Jeff's state of being mute did not stop with speech, but overflowed into Jeff's social interactions with other children. One of the curious situations was that Jeff was unable to eat in specific situations and was unable to go to the bathroom. When Jeff finally did begin to talk, the problem with eating lessened greatly and the toileting problem disappeared at the same time. I found this to be very curious and continue to wonder at this.

Jeff was unaware that he was soon to be discharged from the Children's Hospital to the main city psychiatric hospital. Up to this point in his stay there, he had not been able to talk and his problems persisted. The professionals were beaten by the situation and therefore we should send him to yet another facility to try to make him speak. He finally chose to break the mute state by himself, and the plan was his own as to how he would begin to talk.

With success, Jeff was truly so excited about talking at last, and he requested to go to former teachers and people whom he had known throughout the years in order to speak with them.

The five-month hospitalization was extremely traumatic on the whole family. We were required to be at the hospital several days and/or nights of the week. There were groups for the siblings, special parent groups, meetings with the nurse, meetings with the social worker, special nights for Jeff's dad to be there with him, and daytime activities in which some members of the family were required to be involved. It was a very draining period of time for all of us. As the mother, I was trying to meet the needs of the whole family as well as the requirements of the hospital. My life had turned into a series of schedules, more so than ever before and little time for the other children. Again, I found myself telling the children that this time it would work, that we would find the answer to Jeff's problem. This promise had been made hundreds of times during the previous years and was never fulfilled, and life at home continued to be just as traumatic to all, as usual.

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As I have previously written, life for the other children was not at all normal, no matter how hard I tried to create a normalcy for them. How could that happen? It was impossible, and they lived their lives receiving false promises, being constantly exposed to meetings and people who were suppose to help us find an answer. This situation was the creator and advocate for problems with Jeff's siblings. So many times they would cry and say to me that all they wanted was a normal life like their friends. To participate in activities to have friends over, to not live in distress and terror was a dream to Amber and Matthew.

The social services at the hospital during Jeff's long stay urged us to send Amber away to a summer camp that was promised to be so good for her. That, also, turned out to be a very traumatizing event for her as she had never been away from home alone and was thrown into a situation for which she was unprepared, dealing with girls who taunted her and were very cruel to her. She went to camp with a group of girls who were street kids, and she had never been exposed to that type of situation. Instead of being helpful to us and to Amber this created even more problems.

Following Jeff's hospitalization, both Amber and Matthew had to go into therapy for an extended period of time, because life had begun to crumble around them.

The irony of the entire hospitalization was that, yes, Jeff came out of the hospital talking, but the reason for the autism was never **addressed**, and the underlying behaviors remained. We took him home and the real problems were there. I still had an uncontrollable child who terrorized the family and had yet to experience even more social intervention. Later, during a crisis, when we approached the hospital, we were told that Jeff had been admitted for the mutism, not the rest of his behaviors, to which I ask, if a patient is admitted for surgery and during this admission, the hospital discovers that the patient is diabetic or has heart disease, are they going to ignore this information and do the surgery regardless, send the patient home and ignore the fact that other problems existed? **Where is the difference?**

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## **No One Understands**

### **CHAPTER IV**

#### **FRIENDS: THE IMPOSSIBLE DREAM????**

For me, making friends is very hard, so I don't have many. However, I do have a couple of very old friends. One of them, Matthew, lives up north, in St. Sauveur, Quebec. Another one, Jarma, lived on the other side of the highway from me when I lived in Dorval. I knew both of them when I was in elementary school. Matthew use to ask me to his birthday parties and my mom and dad would take me. But I wouldn't go to the door, and I caused a scene when they tried to get me to go in. Most of the time, they ended up taking me back home with them. It was a very long time ago and I don't know why. I believe I was just afraid because of all the other kids being there. For Jarma's birthday, I always went with him and his family to LaRonde, a great big fun park in Montreal. I wasn't afraid doing that because there weren't so many kids there with us who would expect me to talk. After a day there, we would all go back to our house for supper.

I remember I went to Matthew's house to play a few times and that was O.K. His mother helped us to play together, and one time she made butter tarts for me. I liked them so well, that she gave me the recipe for them and my mom still makes them for me. One time Jarma, Matthew, and I went to the pool, but I didn't swim.

One year, my mom had a birthday party for me at our house. I wanted the party and looked forward to it, but when the kids came, I took off down the road. I was really upset and one of the kids was concerned about me. They didn't understand why I was upset and left my own party. My mom came and tried to talk me into coming back, but I wouldn't go with her. She started back home and after a while I went back by myself to the party. We played games in the back yard and my mom says I was able to relax a bit and join in.

When I left Terry Fox and went to the hospital and to the other schools we stopped seeing each other. Years later, when I went to P.C.H.S., I met Jarma again and we started to do things together. Matthew, Jarma and I did a lot of things together until we moved to Ontario.

Matthew has brown hair and is about my height. He's funny and likes hockey and movies. Jarma is shorter than I, with light brown hair. He is polite, likes computers, and is a good friend. We were all in the same class together at Terry Fox, and are about the same age.

We all use to meet and go to Fairview, which was a big mall in Pt. Claire, Qc. Usually we would take the bus, and always sat in the back and act like cool kids. We hung out and

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looked around the stores, and sometimes got something to eat. We would eventually take the bus to our house and get something to eat. We played UNO, watched videos, and hung out at home.

Sometimes we would go up north to St. Sauveur for the weekend or for Matthew's birthday. This time, I went and had a blast. In the winter, we would slide on a very icy snow hill. Matt had a G.T. and we would take turns on it. Once, he took us around town and showed us his new neighborhood. We would watch movies and go out for fresh air.

There were two girls who use to call me a lot. We only saw each other at school and talked on the telephone.

One of my newer friends, Lori, I met in 1993 at school. She was also my boss. I did jobs around the school that she arranged for me. She is a very caring person who understood me. Whenever I needed help, I could always go to her. She also was one person who helped me and encouraged me to go to the graduation. To me, it was as if we became best friends the very first day or so and we still write to each other.

My brother and sister bring their friends over to the house all the time, and some of them are boyfriends and girlfriends. I feel a bit bad because they can make friends easily and I can't. When I say I want to make friends, I want to be able to start a conversation now and then. But something keeps holding me back. Instead, some other people do that if I am lucky. What I mean by that is, that hardly anybody says "hi" to me. When I meet somebody around my own age, we don't usually become good friends because a few days or weeks go by and then I never hear from them or see them again. Something usually happens, like changing schools, to prevent us being friends. The reason why I can't make friends is because I am scared, shy and a bit embarrassed too. These are answers to questions but they are also questions. Why??? Why am I scared, why am I shy, why am I embarrassed? My theory is that it is an imaginary fear I have in my mind.

When I was in St. Thomas, I sort of met this person through my sister. One day my sister told me she wanted to be my friend, and I told my sister that I would like to be her friend, too. We said "Hi" now and then and things like that.

No matter how long it takes I will never give up and I will always try to make some friends and with a bit of help from my mom, I have some encouragement that will help me to keep at it.

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### **No One Understands**

From Mom's Perspective:

Making friends is one of the most difficult and most characteristic of people having autism/Asperger's Syndrome. They are unable to read the cues that we all experience in our interactions: tone of voice, body language, words with hidden or vague meanings. The concreteness of their manner of thinking allows only for concreteness in their manner of interpreting and therefore their interactions. In other words, what they see and hear is exactly what they see and hear and what they interpret.

These people are many times affected just enough to seem a little odd otherwise appearing normal, which again causes people to shun them. People with Asperger's Syndrome do feel this indifference thus creating more negative thoughts and intensifying their negative sense of self worth. Thus, the high number of suicide in this group of people. What choices do we have if we really don't fit in?

In our society, we frequently fear or shun **people** who seem somewhat different from us. As with Jeff, who has many or most of the same desires and feelings that we all have, it is so hurtful to him to be so aware that he is not completely accepted by society and is not able to make friends. He speaks so frequently about this and how people seem to judge him before they give themselves a chance to get to know him. This only creates feelings of lesser self-esteem than he already has, and makes him feel more the outcast.

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## **No One Understands**

### **CHAPTER V**

#### **SCHOOL**

I was three years old when I had to go to the Dorval Day Care. I don't remember much about the day care. We had the little mattresses that they had on the floor so the kids could take a nap. I remember the square schoolyard. In the winter there was always a pile of snow in the corner. I was in the Sunshine Room (4 year olds) and the Rainbow Room (5 Year olds). I had a teacher named Luisa. She had long black hair and was a nice teacher. We use to see her near the shopping center. I liked Louisa but I never talked to her. The only other thing that I remember about the day care was at winter I use to go on the hill of snow with the other children. I never talked to anybody and I always played by myself. My mom said that I didn't want to go to the day care. I always yelled and screamed and kicked when she took me. I gave her a rough time every day, but she took me anyway.

At the age of six, I started grade one at Terry Fox School. I was in a special class called self-contained which had about ten to twelve students. They all had special needs one way or another and were not able to be in a regular class. We had two teachers, the main teacher and a helper. I didn't talk at this school at all. The teachers all wanted me to talk, but I just couldn't. At one point, my mom came to the school two or three days a week to try to get me to talk. After three months and no success, that ended.

I absolutely never did any schoolwork. The teacher would give me a sticker for anything that I did do, pick up my pencil, open my book, write my name, anything. There were rainbow bear stickers, butterflies, and other colorful stickers. After I earned a certain number of stickers, I got a special treat or toy. I had no choice however but to listen to everything that the others were doing. I guess this is how I learned to read. Otherwise, I have no idea how it happened. I do remember that I use to read for my mom on a tape and I would take it to my teacher so she could know that I could read like the rest of the class. The teacher could not believe how well I could read, and nobody heard the tapes except my teacher.

I didn't do gym at Terry Fox, but at free time, I would play in the gym. I always kept everything to myself; I never played with the other kids. After we ate lunch, we sometimes went to the park to play. Eating lunch was really hard for me. My lunch teacher was Mrs. Joyce. She was a good friend to me. I would only eat my lunch when Mrs. Joyce was there. If she was not there for some reason, I would not eat my lunch. My mom says she always knew when Mrs. Joyce had not been in school, because my lunch came home with me. She says she thinks the **change** alone in lunch teachers made me shut down.

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I never went to the toilet when I was at Terry Fox. I had to change my clothes everyday behind a bookcase in the room where nobody could see me and take my wet clothes home in a plastic bag for my mom to wash.

I had a few friends of a sort. They were kids who were in my class at school. Gianni(Johnny) was a small Italian boy with black curly hair and was very funny. He came over to my house now and then. We were like good buddies. I would talk to him when he came to my house. He thought it was really exciting and cool the first time he came to my house and I said something. Then he started asking me why I wouldn't talk at school. I remember I had a little orange tricycle that I gave him when I got too big for it. It was just the right size for Johnny. Matthew and Jarma were two other friends of a sort.

I spent five years at Terry Fox, and I didn't talk at all while I was there. Because nobody was able to get me to talk at all, I had to go to the hospital for the rest of my grade five year.

The year after that, I began school at ST. John Fisher Elementary School. I was quiet and shy, but gradually I was a bit less. I went to school there for two years and it was time for me to graduate. My teacher wanted me to graduate, but I didn't want to. I mean that I didn't want to go up on the stage to get my diploma. She told me that if I came to the school, she was going to make me go up on the stage. I wasn't going to go to the graduation, but that evening, I told my mom that I wanted to see the class graduate, but I didn't want to go up on the stage. I had decided that I wouldn't go at all and my mom promised me that she wouldn't make me go up on the stage if I only went to see my class graduate. So, that was what we did.

I then went to St. Thomas High School for the next two years. The first year I was quiet and shy again. I was in a partially integrated class. Some of my classes were with the regular kids.

Mr. Enzo was one of my favorite teachers. I was in his class at St. John Fisher the two years before and now he came to St. Thomas the same time that I did. Mr. Enzo was a good friend to me. He and Mrs. McTavish understood me and helped me through those two years at St. Thomas.

The teacher I had for gym use to get mad at me. I didn't like gym to begin with, and I wouldn't wear the gym clothes. He use to get mad at me for that. The rule was that you had to wear gym clothes so that you could do the class. I was too embarrassed to wear gym shorts so people could see what was under my regular clothes.

There was a boy I was a friend with at Terry Fox School, just like Jarma and Matt.

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I was in P.C.H.S. for three years. Early in the first year I was always leaning against my locker. I didn't go to classes or eat my lunch. I just stood by my locker. When a teacher or the principal would see me and ask me what I was doing, I would tell them that I didn't know what class to go to. I became very good friends with one teacher, and she encouraged me to walk with her at lunchtime. We talked and picked up coins that were lying on the floor and we became good friends. She gave me a birthday card. She saw my dinosaur shirt and like it a lot, and when I told her that my mom made it, she asked me to make her one. I drew the pictures and my mom painted them for me. I am pretty good at drawing.

Mrs. Blake-Cote also taught a class on making newspapers, and she and a girl named Natalie, came to our house to interview my family and me. Natalie wrote an article for the school newspaper about me.

Lori was the first person I met at school. The second week at P.C. was when I met her. Lori thought that I was superman because I carried a bag full of very heavy stuff and she teased me about it. Sometimes I was assigned to work with her and some other students who were in the work program as well. I did things like recycling and putting mail in staff mailboxes. Lori and I talked a lot and she helped me when I needed it. She also helped me when it came time for graduation. Lori was a person who really understood people and I consider her as one of my very good friends.

Near the end of my second year at P.C., another teacher asked me to become the curtain manager for the play that the prep fours did. The following year, I was asked to be the Master of Ceremonies for the concert and other plays. An M.C. needs to speak to an audience and it was a great privilege to do it. The teachers coached me, they encouraged me, and they helped me learn how to speak into the mike. I really felt good in doing that.

During my last year at P.C.H.S. I was told about a girl in my school who had the same problem that I have. I was told that she was having trouble with the other kids teasing her, so I decided to try to be a friend to her. I used to talk with her at lunchtime or at recess. She always told me about the kids bothering her, and we talked about everyday things, you know, just chatting. I was also asked to work with a girl from an elementary school, who was able to talk, but for some reason she didn't want to and stopped speaking at all. Everybody was very worried about her. So when they found out that I had not talked either, they thought that I could help her because I could understand her. I took the 203, a city bus, from P.C. to her school and spent a few hours with her to try to help her to talk.

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From Mom's Perspective:

The Dorval Day Care had an excellent reputation and was selected by the doctor at Montreal Children's Hospital, because they not only accepted children with special needs, but the staff was experienced and open to working with these children. It was also thought that if Jeff were with the average child daily, that perhaps he would relax and pick up some of their behaviors. At this time, it was unknown as to what the source of Jeff's behaviors was. Jeff was selectively mute.

Jeff fought going to the Day Care constantly. It was always a struggle for me to get him there, but I soon learned that I could only take him, give him over to the teachers and leave quickly. He failed to speak a word during the 3 years that he was there, but eventually learned to be taken into activities however docile he might be.

At any functions, Halloween, Christmas, etc., Jeff would hide beneath the tables. He refused to eat or drink refreshments during these activities or to actively participate in them.

He never learned to interact with the other children, nor did he pick up on their "normal" behaviors as had been hoped. He only developed a bond of a sort with one of the teachers who were especially interactive with him. Jeff left the Day Care, still mute, still withdrawn, still not eating in public and still not toilet trained.

Still, nobody knew what was wrong with Jeff and so many efforts had failed to make him communicate verbally or to stop wetting himself. The people at the Day Treatment Centre of the hospital continued working with us, as we had no other real supports.

Jeff was too old for their program at this point, but they made exception as we had a very unique situation and were in desperate need of help of any kind. One worker came to the house and worked with Jeff one on one. She used all of her skills to get him to talk. They would work together at home or would go on outings, but nothing was successful. I could feel the compassion from the people who worked with us from the Day Treatment Centre. It seemed that they were very much aware of the uniqueness of our situation and did everything they could to help us. However, we eventually outgrew them and were forced to move on.

At Terry Fox, Jeff continued to be mute and was unable for whatever reason to participate actively in the learning situation. The focus became getting him to speak and getting him to use the toilet.

The staff felt that it would be better if Jeff were not to go to the main washroom to change to prevent his being teased by the other students in the school. However, at one point the new principal decided that they would just have to humiliate Jeff as a last resort into using the toilet. She thought that the tough way would force him into going to the bathroom. So she placed him on a chair outside her office when he wet himself, so the other students would laugh at him, humiliating him, therefore breaking him from wetting himself.

This lasted one day and I stopped it very quickly. I knew that Jeff would not respond to that kind of treatment when he couldn't respond to the kind, loving, encouraging methods that had previously been in place. This incident was the last before the new principal and new teacher decided Jeff could no longer remain at Terry Fox School, even as special

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needs. It was at this point that Jeff was to be sent for the five-month stay at the Children's Hospital.

After the five months on 7D, Jeff returned the following year to public school, and new one to him, which again, offered self-contained classes along with some minimal integration into the mainstream. He was there for two years, during which there was no progress as far as education and his behaviors.

Jeff continued to behave very aggressively at home. The earlier screaming had turned to fits of rage with his breaking holes in the walls and doors, throwing and breaking things, terrorizing family members and friends by striking out verbally and in his actions. The one positive element I might add was that Jeff never intentionally physically hit anybody else. He just frightened them to the point of their being afraid of him.

At one point, we strongly considered placing Jeff in the psychiatric hospital because I could barely keep up with his aggressiveness and was receiving no tangible help. I personally suffered a burnout resulting in my being hospitalized for a month.

The professionals, educational as well as social and medical, held a meeting at which was determined that there was no problem with Jeff, that he was perfectly normal, and that he would one day be no different from anybody else. As a result of this meeting, there was no placement for him and we continued for years to come fighting the battle by ourselves. I continued to try to raise Jeff to the best of my ability and also two other children who also needed a mother.

On the night of the graduation from St. John Fisher School, Jeff came home very low and I asked him if he had changed his mind and reminded him that he could still go and that his teacher would be very happy. He continued to say "no" but was quite down and pensive. So, knowing Jeff, I asked him if he would just like to go and watch his class graduate. He said that his teacher would make him go up on the stage if he showed up at the school. I sensed that it was important to Jeff to go to the graduation, but that he was stuck in a dilemma. So, I promised him that if he went, I would see to it that he would not be forced to go up on stage. The real problem as it turned out was that at practice, the class was asked to stand and sit many times, and it would be in front of all those people and that he was not ready for that. We went to the ceremony and Jeff proudly watched his class. The teacher did, in fact, come to Jeff, took him by the arm and was determined that he was going up with the class. I believed that this would have been destructive to Jeff at that point. Being aware of his fears, and his reactions, I refused to allow him to be taken against his will, and forced to participate in this type of activity. Incidents like these had occurred too many times before and had caused Jeff to shut down for long periods of time and sometimes permanently.

When Jeff entered St. Thomas High School, Jeff was placed in a special class situation as well as being minimally integrated. The main focus for three years became to get Jeff to dress in gym clothes, so he could be allowed to do gym. No matter how hard I tried to explain to the special education educators, I could not make them understand the uniqueness of Jeff and that he could not be made to fit their system, but there needed to be some flexibility in order to work with him. It always rattled my mind that the so-called special programs were so rigid that they couldn't be altered to fit the individual. Therefore, after three years of this stuff and the inability to make Jeff adjust to their system, remember Jeff wouldn't put on the gym clothes and God forbid that he could

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### **No One Understands**

wear sweat pants to do gym in, Jeff was again going to be shuffled off to yet another school, but better program.

We were told that P.C.H.S. offered a program that would be perfect for Jeff. It was suppose to offer him flexibility and allow him to learn in his way. We even went to that school to meet with the head of that program. I noticed that he himself wasn't too sure, but with the influence of the former school, accepted Jeff into his program.

Here, I might add that each year, the starting up of school for Jeff was a major effort, even if he were continuing in the same school and with the same teachers. There was a great deal of planning and preparation required on the part of the teaching staffs and myself to make it work. I had to send my other two children off many times with minimal preparation as Jeff required so much of my attention. Every small aspect of Jeff's entering school each year was considered and acted upon and required at least two weeks of work to just get him there and into the hands of the educators.

So, in September, Jeff was to start the new school, new program. I knew from the first day, that it wasn't the right program after all, but in view of the fact that my input was invariably vetoed, I decided it was past time to try to help, but for me to allow the professionals the privilege of seeing for themselves just what the challenge really was, so I kept quiet.

Within two weeks, the head of the special needs department phoned me, telling me that Jeff was wrongly placed and the only thing they could do was to put him in a self-contained class setting where he could possibly be given chores and responsibilities to help with other students. They were so surprised that Jeff was not functioning in the former setting and felt that they had been misled.

So Jeff was transferred to another class setting called prep four. He really didn't belong in this class, as most of the kids were lower functioning than Jeff. But Jeff was not as socially developed, and this along with an experienced teacher, proved to be, not only the ideal setting for him, but the one that would change his life.

Mrs. Blake-Cote was a teacher who had seen Jeff the year before at St Thomas and her heart went out to Jeff as he clung to the locker. She approached him and began to talk to him. After he began to respond, she then asked him to join her as she supervised lunchtime. That first week with her made a tremendous impact on Jeff. Lunch duty for the staff was a week at a time, but when the principal, Mr. Bernard Young, saw what was happening, he approached Mrs. Blake-Cote and asked her if she would continue so as to further help Jeff. His concern for Jeff was as deep as that of Mrs. Blake-Cote. This lunchtime friendship grew and continued for several weeks until Jeff felt safe and comfortable within the school environment.

Jeff began class with another extraordinary teacher who was firm and had expectations, but expectations that she sensed were **realistic** and within Jeff's reach and this was exactly the type of learning situation Jeff had always responded to at home and which the teachers before had so frequently missed and seemingly refused to accept.

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One evening, Mrs., Mastronardi phoned me to ask me what Jeff's diagnosis Jeff had. I told her that we did not have a diagnosis, that the professionals with whom we had been in contact with to this point felt that there was nothing wrong with Jeff. I, however, had through some experience strongly felt that he had autism. Doctors before had refused to acknowledge that the signs and symptoms described to them by myself were of any value and therefore had discounted autism as a possibility for Jeff. Mrs. Mastronardi had worked at a psychiatric hospital before and had a great deal of experience with all types of personalities. She told me that she, too, believed that Jeff had autism and gave me a contact that would direct me to an expert who might possibly see Jeff and perhaps supply a diagnosis. These events supplied the missing information and resulted in a lifetime changes and challenges.

In the three years, following the rough start, Jeff grew more than he had in his lifetime. He went through a metamorphosis that I never dreamed could take place with Jeff. He changed immensely from a terrified, unhappy human being to a fairly happy, no longer frightened individual who had begun on a road to tremendous growth and maturity. Thanks to all the good people at P.C.H.S. who had the knowledge and the caring to look at and give each person in their care unselfishly, complete devoted parts of themselves. Jeff learned to smile and to talk with other people, with a growing self-esteem, and was given a great send off into the world as an adult.

# *A RAGING SILENCE*

## **No One Understands**

### **CHAPTER VI**

#### **SPORTS TO DO OR NOT TO DO?????**

There are a few sports that I like and that I'm good at but don't play. One of those games is basketball. I like basketball because I like the feeling of the ball going into the basket. Some people say that I would be good because I'm big enough.

I also like playing soccer baseball but I never play it except when I did gym in school. I really enjoyed that sport. Once when I was in St. John Fisher, I played a game of soccer baseball and it was my turn to kick the ball. I kicked the ball so hard that it hit the light in the top of the gym and a lot of dust came off. The light swung back and forth and everybody laughed. I didn't know that meant I was out, but everybody wanted me on their team anyway. I was a good kicker and a very fast runner.

Years ago, my mom or dad signed me up for soccer in Dorval. First, we did some exercises but I didn't do them. Sometime after, I went to my first game. I walked to the field because it was only a few blocks away from our house. I wore a uniform with a shirt that was sky blue and had a white number on the back. I wore it to every game but I never played. I don't know why but I guess I was shy and scared. In the middle of the game they always had oranges for the team, but I never ate any. I don't like oranges, but I probably wouldn't have eaten anything they had. The last game I went to see who won the season, but we lost. I didn't care, after all soccer wasn't my thing.

After some years, I played baseball. I was on a team called the Blue Jays. The Bluejays had a white uniform with two stripes down the side of the pants. The shirt was red with dark blue sleeves and red, white, and blue stripes on the cuffs and around the neck. The baseball hat I used to wear was not bright, but dark blue with a white circle and some lettering in it. It's a few centimeters across and it was in front, on the side, and in the middle of the hat.

I was in baseball for two years, and the first year I was on the Bluejays. We were very good because we could beat all the other teams except for one. The one we couldn't beat were the Yankees. But we did beat them in the playoffs. My team was excited, especially me. At the end of the year, we all got trophies and so did everybody on the Yankees.

Sometime during the season we played against the Expos and we won by about thirty-some points. They were very good though. The Expos had sky blue uniforms with dark blue numbers and the same kind of hats.

A year went by and I was in baseball again, and this time I was on the Twins. This year I wore a different uniform, which was a gray and the hat was the same. Then on day the

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uniform was changed. It was all black with a bit of white down the sides of the shoulders and down the side of the pants. Everybody wore them except me, because I was too big for the pants. So I wore the black shirt only and the gray pants. When we played baseball on a sunny day, the black shirt sort of started to sparkle in the sunlight. I always felt good after a game.

When I was a Blue Jay, I played baseball at the home field, which was at the community center near our home. In right field there wasn't much action except for one time. It was pretty dark and some kid was up to bat. He finally hit the ball and it headed towards me, but I didn't catch it. The ball hardly ever came to my side of the field and I wasn't paying attention when it did come to me that time. There was another time when I was up to bat. I went up to the plate and got ready to hit the ball. I hit the ball and it went very far. It could have been a home run, but I hit it into foul territory and right over a batting cage. After that, I couldn't stop laughing for a few minutes.

When I was on the Twins, I was also in right field. I was again out of it time to time, but I enjoyed it anyway. It was really fun and I liked baseball.

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From Mom's Perspective:

When Jeff began soccer, I felt he should be integrated into some summer activity within the community. After much discussion, we, along with the community decided that soccer could be the answer. We first took him to the tryouts, where he ran against the coach. HE ran so fast that he was readily accepted. He was really excited to begin, however, when practice and game time came, Jeff refused to participate. The interesting thing was that although he wouldn't play, he still considered himself part of the team and never missed a game. He spent every game, running up and down along the side of the field as the team moved. At the end of the season, he was so excited for his team to win the trophy, and seemed disappointed when they lost to one team.

Several years later, he wanted to play baseball. Again, the community was eager to be part of the integration process and Jeff was placed on a baseball team with a very understanding coach. As we lived very close to the fields, and we wanted him to become more independent, we thought it a good idea if Jeff left for the fields by himself as so many of the other players did. We would be there in time for the game itself. We began by going with him at first until we thought he had enough initiation. Then it was time for him to try to go on his own. It was very interesting, because he readily got on his bike and started off. But as he got in front of the house, he started circling in the street. He

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did this for several minutes, probably trying to get up the courage to make the trip by himself. Then off he went. After that, he would ride over to the field on his own, and we would join him later at the game. I was really excited about this step for Jeff, as each step he made on his own was a huge step in his growth.

He also attached himself to only one of the coaches, which is also typical of people with autism/Asperger's Syndrome. When involved in any type of activity, they will select one person with whom to attach and usually that is the only person with whom they will outwardly interact. Jeff attached himself to the coach and when he would give Jeff an instruction, Jeff would do it, but when the assistant coach would instruct him, even though Jeff might know what to do, he would not do it. He really did seem to have so much fun

that summer and accomplished a great deal as far as growing toward independence and overcoming some hurdles.

The following year, Jeff got off to a rocky start. I took Jeff to the tryout field, but had to leave him there under the supervision of his former coach from the year before. I explained to him that I had an errand to run and would return within the hour. Knowing that Jeff was familiar to him, I figured he would be OK. When I returned, himself, looking very quiet and sad, seated Jeff on the hill and all the other boys were out on the field practicing. I asked him why he wasn't with the others and he told me that he hadn't tried out. It turned out that because all of the activity of the event, the coach had forgotten about Jeff. The list of names for our area had been missed and each boy had to make himself known individually in order to try out. The coach had been very busy and had forgotten about Jeff and of course, Jeff was unable to make himself known. Therefore, he was completely missed. This was a negative beginning for him and he was unable to regain the excitement that he had the previous year. To add to this, new uniforms had been purchased and Jeff's did not fit. He refused to go into the locker room where the other boys were trying them on and therefore couldn't be fitted. He had never been able to change clothes in front of others, so I don't know for sure if this was the reason or if he could not make himself go into a room with so many other boys unfamiliar to him. Jeff had lost his enthusiasm for baseball that summer, it seemed and refused to play on a team again after that.

He was able to spend some time during the summers to follow, playing with his brother and some boys from his school. They would play baseball or basketball. One of the happiest days for me was when he came home with a huge tear in his brand new jeans and a great big laugh. He said, "Mom, I slid into base and made a home run." That was one of the biggest rewards that I received from Jeff, he had been with other boys and had a great time, felt really good about himself and was so happy. Who could possibly care about the new jeans?

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Jeff did very well in swimming as this was a one on one activity, and he was with specially trained instructors for the “aquadapt” program. He really never cared for swimming, but did in fact, learn to swim quite well.

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## **No One Understands**

### **CHAPTER VII**

#### **HOBBIES, HOBBIES, HOBBIES**

I have some hobbies that interest me. My favorite is space. I like it so much that almost everything I have has to do with space. I have over ten *Star Trek the Next Generation* books and I put them on a shelf in my room. I've read almost all the ones I have but there are a lot of them that I still don't have.

I also have three *Star Trek* models, one from the original *Star Trek*; another is from *Star Trek the Next Generation*, and then from *Star Trek Deep Space Nine*. The original *Star Trek* is the U.S.S. Enterprise, which has lights and sounds. *The Next Generation* also has the Star Ship U.S.S. Enterprise but doesn't have lights or sounds and *Star Trek Deep Space Nine* is a space station. I usually needed help from my brother or my dad to put these models and others together. I also have some *Star Trek the Next Generation* and the original *Star Trek* collector's cards. There are three hundred and ten cards in the set and I have most of them. I'm having trouble finding the rest of them. I am collecting the movies of all the *Star Trek* episodes. I get one cassette with two episodes every month or so. I have at this time almost half of the entire collection. I have playing cards that have the picture of *Star Trek* on the back and a *Star Wars* monopoly game on the computer.

I also have a telescope that was a present given to me by my mom's friend, Vicky, for my graduation from high school. I have seen a few planets including Jupiter. Jupiter is the most amazing and beautiful planet I have ever seen. I have a calendar that tells me when I can see specific things on certain nights.

My old room before we moved had a mural of space, which was called Saturn and Three Moons. There were glow in the dark stickers of planets and stars on my walls and ceiling. I have a different mural of a shuttle in orbit now.

My other hobby was dinosaurs. I was interested in dinosaurs because they were amazing creatures that lived interesting lives. I use to draw some of the dinosaurs without tracing them. I just looked at them and I started to draw. I have a book full of dinosaurs that I drew.

Another hobby or partly was stamps. One day my dad brought out a box of stamps, which he had collected for me to look through. I picked out some of the stamps that I liked and got a blue collector book to keep them in. My dad helped me find the order where they went. I got some new stamps when I got the blue book. I still have the book but I haven't put any in since. This hobby died out because I really wasn't very interested.

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I have recently learned to play chess on the Internet with other people all over the world. We talk while we play and sometimes there are some people who are a bit rude. I mainly lose, but I have fun. I like to play chess and I bought a beautiful special set when I went to Medieval Times one evening. I am also learning how to use the Internet and to find things that I would like to know.

# *A RAGING SILENCE*

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### **CHAPTER VIII**

#### **FEELINGS: ARE THEY REAL OR NOT????**

A cloud that wants to rain, but just can't for some reason. Then when it finally rains, it pours. It's like it's constantly flowing down. Until five years ago, when we found out what was wrong with me, my life was hell.

I never got to do what I wanted, like making friends or talking. I wanted to talk so much that I was **upset and frustrated**, but I couldn't do anything about it. I **couldn't even show that I was upset and frustrated**. I couldn't tell anybody, not my family or especially people outside of my family. It was like I was drowning and I was gasping and struggling for air, but no matter how hard I tried, it kept pulling me down. What really kept me going was my will, which was so strong that it was like a life preserver for me.

I must have wanted to make friends then as well as now. When my sister and brother had birthday parties, I was always very upset and angry. **I was jealous**. They seemed to have a lot of fun and enjoyed their friends, but I was unable to be that way. Because of that, I always tried to ruin their parties, and usually succeeded until my mom realized what was happening and had my dad to take me out while they had their friends in.

Not talking and not being able to make friends made my life like a mid-life crisis. All I was left with was being alone. Everything was going wrong with life, everything that a normal person has, I didn't have. This made me very angry.

Today, I'm still very angry because it upsets me the way people treat other people with Autism. They avoid you because you are different. It upsets me when I know that kids are kicked out of school because of behavior that they cannot control, or they are picked on by others for being different or teased or just plain ignored. Nobody should be treated differently, because we are all human beings, made by God, with feelings. If a person can't even control his behavior, how can he stand up for himself against these kinds of people?

It also upsets me because I have this disability. I can do what I want to do but I have to have a little bit of help. I still have trouble making friends. People still treat me like I'm different. I have to wait for people to help me to do what I want to do and usually people are too busy to do some of the things that are needed.

In my experiences, every time I think I'm having a friend, I always end up with it not working out. If I do feel bad about this, it's not much because I guess I'm use to it. I would say that I'm just a bit disappointed.

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I don't like it when people tell me that they are going to help me do what I want to do and they don't for whatever reason. I feel like they are using me. They waste my time and I might as well not bother.

I don't really feel positive feelings inwardly. I do feel happy and caring. I wake up every single day and feel fear. I am afraid and worry when my mom is gone and I will be alone. Sometimes I feel as if I might as well be dead because every negative thing in this world is aimed at me. When I feel this way I feel that nothing goes right for me.

I feel guilty if I know I do something or might do something wrong. Depending what the situation is, I say I'm sorry.

I use to feel positive feelings inside but it seems like those kinds of feelings sort of grew out of me. I no longer have them in my mind or in my heart.

I do get excited when something good happens. For example, I got my driver's license and I can help my family out when they need somebody to drive for them. When I accomplish goals that I have set for myself, I feel pleased with myself, like when after four years I managed to get my drivers license.

The world thinks that people with Asperger's are unable to have fun, but when I went bowling with my sister and her boyfriend, I was laughing and having a good time with them. They don't treat me like I am different, but have the same expectations as they would with anybody. They invite me to go places and do things with them and he accepts me for who I am, and that is very important.

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**CHAPTER IX**

**PETS:  
A BIG RESPONSIBILITY**

Some people have cats, dogs, birds, fish, lizards and rabbits. My whole family, almost, is allergic to animals. The very first pet that I had was a gold fish. I was small then and didn't know how to take care of pets, so it lived a while and then it died.

I had to take care of a guinea pig for the weekend. It was the class's pet and I didn't mind taking it home with me, as a matter of fact, I was happy to do so. I brought him home and took care of him, myself. I fed him, changed his cage, and played with him.

Another pet that I had was a turtle. We use to take him out of his bowl and play with him on the floor. One time he went behind the cabinet and he hissed at my mom when she tried to get him out. He didn't last long either. My family decided to get rid of him because we didn't take care of him, so we gave him to some friends of ours who had turtles and they took care of him.

Sometime went by and I got a hamster or a gerbil. I can't tell the difference but it was one or the other. This time I was a bit older, and this time I took care of him. He lasted a bit longer than my other pets, but he died from a disease called 'wettail'

After a few years, I had another pet and this time it was a hamster. I thought it was a male so I gave it a male name, but it was really a female. One evening I went in my room and I just decided to look at the hamster and I had a big surprise. She was a female and she had babies, three of them. When I saw them I started to laugh and laughed so hard that tears came to my eyes and my stomach started to hurt. I went downstairs and tried to tell my mom and Amber, but I couldn't get the words out. Finally, I told them and went back upstairs. They followed and they started to laugh, too. It was neat having four instead of one. In a few weeks, they were big enough without having the mother get mad, so I gave one to my brother and one to my sister.

One day, I found out that they were not in the cage and they were in the house somewhere. We couldn't find them anywhere. Time went by and then I found that they were stuck in a wall. We got them out one time, but another time we couldn't get them out because we would have to take apart a wall and my mom and dad said "no" to that. They ended up dying there.

One Christmas, I got a birdcage and I was real happy. A few days later, I got a budgie. His name was Chipy. He was a bit yellow, green, black, and very little blue green. He was very bright because when I told him it was time for him to go in his cage, he actually did. He did a lot of cute things. He would fly around the house knowing exactly where

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he wanted to go. He landed where he wanted. He had some favorite toys, like a mirror, which he banged against the cage and a bell, which he played with all the time. He would go outside the cage and take the swing down and try to beat it to the bottom of the cage. I had Chipy for seven years and he was a very good friend to me. I use to talk to him and play games with him. He died when he was seven years old. I miss him, but I've had enough pets in my lifetime and I don't want anymore.

My sister had two budgies and they were both females. One of them was dark bluish purple, white, and a bit of black. Her name was Tenese. The other one was bright yellow and a bit of black and her name was Tweety. They were two or three years old but they didn't live long. Tweety was not well so she went to the doctor and she had to be put to sleep. Meanwhile, Tenese, who knew that Tweety was missing, committed suicide. She started doing some really strange things, like climbing into the feeding dish and getting caught. She apparently suffocated herself.

Another pet that we had was a rabbit. We got him when he was six months old. Hi name was Abu. Abu was brown and had a patch of gray. We had him for about a year, and then we gave him away. Amber was allergic to him and couldn't take care of him, so we gave him to a friend of ours, who lives on a farm and he gets taken care of. I missed him a lot.

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### **CHAPTER X**

#### **GRADUATION: A STEP TOWARD INDEPENDENCE**

It all goes back to my sister, Amber's graduation where this whole situation started to form. In May, 1996, which was the year that my sister graduated about one or two weeks before I did.

It was a normal day for me. I got up and got ready for school, then went to school and at the end of the day I came home. Meanwhile I didn't know what Amber was doing except for getting ready for the big night. She asked me if I would like to go to her graduation and I didn't want to go because of a personal reason, but I went anyway. I didn't want to go I didn't think it was a big deal, but it was, and I was wrong.

Well the time came and we went. The graduation was held at St. Thomas High School in the gym. The gym had a camera and hundreds of seats and the gym itself is almost as big as a soccer field. We went to sit down on some orange chairs that were lined up in a row. A friend of the family came too. After a half an hour or so the graduates came from the back to the front where the stage was. They were lined up two by two and they were walking with normal strides. As they came, people were starting to stand up one by one until everyone was up except me. I wasn't in a good mood because first it took so long to start and finish, and second I was a bit jealous. Well they walked by us, so I straightened my back and sat straight up. I turned my head so it would line up with my shoulder, saw Amber with her head up and looking straight ahead. A few seconds later I dropped my proud looking shoulders and relaxed. Another few seconds passed and everyone started to sit down one by one.

Finally, the ceremony started, the principal, some other people that work there, and a student that was going to graduate talked.

A few hours went by and the time came after all the rewards and plaques were given out, all the graduates had their turn. Someone went to the microphone and then the person got ready to call out each and every single person to come up. The first person went up until he got to the top and waited until he was called to get his diploma. The second person that was in the first step, getting ready to take the place of the first person up. As soon as they got their diploma and their picture take, they went to the end of the stage, went down the steps and went to their seat again. When they went down the steps, they sat in the same order as they did before anybody graduated. When there was at least one person left in the line, another line stood up and went to the stairs, which lead to the rectangle stage, until all the graduates received their diploma. After they were all standing up, the principal went to the mike and said with a proud tone in her voice, "I now pronounce you the graduates of ninety-six." All the time that they were standing, they were like security guards guarding a bank from thieves, but when the principal said those words, everybody took their hats and threw them in the air. The gym was full of

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smiles and flashes of light from cameras. The cameras stopped and the cheering of the graduates stopped.

They were finally quiet and a few girls walked on the stage, picked up microphones, and started to sing. While they were singing, the graduates started to sway back and forth with all the weight on one foot and the other foot very slightly off the ground. Sometime after the song was over and the swaying stopped, the principals, vice principals and teachers were starting to get up and walk to the back of the gym. They walked two by two, then the graduates followed in the same way that they came in, but this time, they were heading to the back of the gym and down to the cafeteria. After a few minutes, my brother, mom and dad, a friend, Michelle and myself went out of the gym to wait for my sister, Amber.

The gym was clearing fast and soon the halls were being filled very fast, so we had plow through the crowd as if we were trucks through a snow bank, but this was easier. I was still a bit stubborn, but now I was tired and relieved that it was over and I still didn't see what was the big deal.

Some time went by and then Amber came back up and met us in one of the long hallways. We talked to Amber and then Amber took Michelle on a tour of the school. My brother, Matt and I decided to go with them, even though we knew the school. After, I went back to the cafeteria and cut through the crowd. I went left and I went right until I reached the cafeteria and then when I did reach the entrance, I slipped in and stood aside until I saw Amber. I then saw my mom and dad. Now we were all there and we talked to Mrs. Blake-Cote, who had been my friend and a teacher at P.C.

Then my mom, dad, and myself went to talk to somebody else while Amber, Matthew and Michelle went to see some other people. People were all around us chatting with each other. Finally it was time to go and I looked for the rest of the group all over the huge cafeteria. One by one I found them and told them that it was time to go. Eventually, the little group was together again and then we finally left the H shaped building and into the darkness. We went through the parking lot and headed for the sidewalk. We walked on the sidewalk for about four or five minutes. During the time we were walking, I felt a bit jealous because Amber graduated, so I was walking a few meters in front of them with my hands in my coat pockets and my head down and looking at the sidewalk as I went by. Now and then I would look back and see the proud group and wonder when they would cross the road. They finally decided to cross, so I crossed too, and then we reached the car. After a few seconds we all got in the car with my dad behind the wheel. My dad drove us to a place where they made cakes and pies. It took us about twenty minutes to get there and through out the twenty minutes I was quiet, looking at the night sky and thinking about things while the whole car except for my dad who was concentrating on the driving was chatting and very happy. After we got there my dad dropped us off at the door while he went to find a spot to park. While he was looking for a spot we went up to the door and opened it. We opened another door and it closed all by itself right after the last person of our group came in. A few seconds later a waiter or a waitress came up to us and said in a friendly voice how many we were. Someone in the front of the crowd said six in a non feeling, very quick voice. Then the waiter or the waitress looked around and found a table and one by one we followed. By that time my dad was with us and then we began to sit down. We were sitting near a window, which

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was beside the door. While we were still sitting on the nice comfortable chairs, a waitress came and asked what we wanted but we didn't know. She left us alone to think about what we wanted and a few seconds later we all got up and went to the counter to see all the cakes and pies in the showcase. After a good minute or two of looking at all the cakes and pies we went back to the lovely rectangle table. Finally, after sitting back in our places for some time, the waitress came back with a pad and pencil and took our orders. The waitress left us, and a few minutes later came back with the food and drinks we ordered. We ate our food and drank our drinks, which happened to be very good. During that time, my family and Michelle were talking among each other and they had big smiles on their faces except for me, unless someone asked me something or made a statement. Throughout that time I was quiet because I was a bit disappointed and felt bad. I felt this way ever since Amber graduated, even being jealous. They still talked after they finished eating. It was about twenty to thirty minutes later before we all got up and went to the cash. My mom or dad paid, while the rest of us went through the two doors and headed for the car. Now we were all in the car and headed home. We finally got back home and we all got out except for Michelle, because my dad was going to drive her home. He left and brought her home and while he did that, I was getting ready for bed because it was around twelve o'clock. I finally got in bed and went to sleep. Friday passed and then the weekend. Monday came again I woke up just like usual, ate breakfast before the bus came, got on the bus, went to school, came home in the afternoon and so on during the whole week until it was Friday again. I till didn't think in this point in time, that graduating was such a big deal. It was the last day of school before the weekend, so I went as usual to school and back. The weekend was finally here which I was happy for. A weekend is very short and it goes very fast. The weekend so fast and it was all ready Sunday. Monday finally came around again and I woke up, got dressed, ate, and got on the school bus. After about twenty to thirty minutes on the large vehicle, it went in a space where busses went and slowed down and stopped. While motionless, a few passengers stepped out of the bus and headed for the large school building. I got off the bus a couple of seconds after the others did; think that it would be another one of those days where I would be bored. The day was what I thought it would be, but then the period came for me to go to Lori's office, where Lori and I talked for a while. Then I went to do my job delivering messages, and returned to Lori's office. While I was sitting in a chair near the door, somebody came into the office and saw me sitting down in the black chair. She came in front of me and she knelt down and we started to talk, then she gradually blended it into the graduation. I was starting to wonder how she knew that I didn't want to graduate, so she asked me if I would go through the graduation, but I said "no" because I would look like a girl and dumb and I didn't think it was a big deal. She told me just before she got up to leave that she will be back every day until I say I will go.

After she left, I asked Lori who she was and Lori told me she was in charge of the graduation and from then on I understood. The rest of the day was boring and tiring. The next day was Tuesday and I had one less day to think about the graduation and I was running out of time fast. During the time I was on the bus, I thought about it, but I didn't come to a decision. At the same time as the day before, I went to Lori's office, as usual,

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and I remembered what the person said to me, so I was expecting her to come. While I was sitting in the same black chair, after my job was finished, the person who was in charge of the graduation came in and Lori and myself said “hello” in a relaxed and friendly voice and she said “hi” with a friendly smile. Again, she came to me with some smooth regular steps to me and asked me if I will go, but I still said “no”. She stayed for a few minutes and we said goodbye. As Tuesday ended and through the hustle of students going to their lockers, I too ran to mine and to the bus. As I hopped upon the steps of the bus and was heading for the back of the bus, I was thinking whether or not I should graduate. I didn’t know what to do and besides, I was tired and hungry. That evening I thought about the graduation. I put Chip to bed and I went to bed, thinking about it, but I went to sleep and slept well.

The next day was Wednesday and this was the last day that I had to think about the graduation. At school, I went to one of my classes and I couldn’t wait until the class ended because it was boring and it was one of the longest fifty minutes of my life. As I was on my way back to my locker, I was aware of the students scurrying left, right, up and down and going to their classes and the echo of their voices in the halls. I managed to get out of the crowd of teenagers and get to my locker. Sometime after, it was time for me to go to Lori’s office, so I went to her office and I leaned on the jam of the door at a ten degree angle for a bout twenty seconds. I looked around and said “hi” to Lori and an old friend of mine and they said “hi” back. For those twenty seconds, I had a smile on my face and Lori asked in a curious and excited tone in her voice and a smile on her face, what was going on. I told her I decided to graduate and Lori said something in an excited voice and so did my friend. After a few moments the person who was in charge of the graduation came in and started to say something when Lori interrupted and said that I would be graduating and she was so thrilled. The rest of the day went by as usual and that evening I had to do my paper route.

The next morning when I woke up, it was Thursday, May 30th, the day of my graduation. I got ready for the bus and put on a different jacket that day. I didn’t need my school bag that day. When the bus arrived at school, I went straight in and started looking for Lori. I saw he in a doorway of the classroom, so I headed toward her. Beside her was another person who was going to graduate with me. I went to school with him at Terry Fox. After we talked for a short time, we went across the cafeteria and opened a big brown door.

From the time I went to see Lori, I was shaking a bit, and the feeling inside me had overwhelmed me. I was a feeling of being excited and happy and nervous, and I felt that way the whole morning. We walked from the brown doors to the stoplight and crossed to the arena where the graduation would take place. The second we got to the entrance of the main arena area, I looked all around and I saw about a thousand chairs set up in a very neat way with an aisle through the middle. On the big stage to my left was a little pot of flowers and behind these were a few rows of chairs. Behind the chairs were yellow curtains with very large symbol of the school on them. All the graduates were they’re sitting in the chairs that were in the front of the stage. Lori first helped Daniel to find his seat and then talked with the teenager beside him, who would help him if he got

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confused. Then she showed me where my seat was and talked with a graduate next to me who would help me as well.

The principal was talking and while I was listening, the pain in my stomach was still there, but I didn't think I would throw up yet. After the principal stopped talking the pain got worse. Lori came up and checked on me to see how I was doing. She stayed close by Daniel and me. When the principal had stopped talking, we all went out the back of the arena by two big doors. The principals took about fifteen to twenty minutes to line us up two by two and when they finished the line looked like a huge banana or moon shape. We practiced walking into the arena, toward the back and right slightly and then straight ahead, between the chairs. The girl beside me told me to slow down a bit, and I told her that I was sorry, and slowed down to match her pace. We again turned right and headed in the direction of the stage. There were a lot of cords and electrical equipment to step over. As we got closer to the stage, we turned into our row of chairs and found our seats. The principal commented on our good performance.

We then went into another part of the arena where we stopped in the middle of a big open space. I was a bit confused and my stomach erupted with the same sick painful feeling. The line started to move quite a bit and then my buddy saw me move out of the line. They called to me to get back into line. The reason why we practiced this was because if it were raining, we would be in this second rink instead of being outside. We walked back into the bigger area, walking swiftly and standing up like soldiers in the army. We walked with our shoulders relaxed and smiling. As we walked, I began to feel relaxed and the pain in my stomach eased up. We again went to our seats and then broke up to go back across to the school.

There, we again got into line and walked into the auditorium. There was a place where the graduates sat and an area for the students to sit. As one person was talking, I began to feel nauseated again as thoughts were running through my mind. I was trying to decide whether I should go on stage to get something that was being handed out to us. When it came time for my row to go up, everybody went up except for me, so I stood up and let the other students pass by. As I sat down, I felt really sick, and I turned my head around and looked into the crowd of parents and saw that someone was staring at me, which made me feel so uncomfortable. I turned around and sank far down into my seat. We then left the auditorium and my mom met me outside in the hall. We had to go get the black dress like outfit and that square Mickey Mouse shaped hat. The hat was black as well with the black strings hanging down. Attached to the strings were the small numbers 96, in gold.

After we got the graduation outfit, we started to leave. We were in the car and I told my mom about the cross that they had given out at the service that was what the students went up to get. I looked out the window so my mom wouldn't see me crying. She thought that I was crying because I didn't get the cross, but that wasn't true. I felt bad because I messed something up, and didn't tell her. She insisted that we go back and get the cross. It was a black string with a little wooden cross hanging from it. When we left the building again, tears once again built up in my eyes. My stomach was OK now, but on the way home, tears rolled down my cheeks and I was very still. Mom saw me crying and just put her hand on my hand. She tried to talk to me, but I didn't say anything or

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move. I finally stopped crying after a few minutes and I didn't move anything except my head, which I move slightly. I was now concentrating on getting ready for the graduation. The real reason that I was crying was that in being Non-Catholic, I wasn't sure if I could accept the cross, and I was not able to make that decision for myself. I wasn't sure if it was the right or wrong thing to do. On top of that, when I looked around and saw myself being stared at, it made me feel even more so that I am not normal. My stomach was filled with the feeling of nervousness, but it was very mild so it didn't really bug me much.

When we got home, I tried to find someplace to hang the graduation outfit, which was in a plastic bag.

During the commotion, my dad came half way to the door and stopped in the middle of the staircase. The dark brown banister sloped downward like a slide at the park, and my dad was standing there, the banister between his shoulder and his elbow. He was standing there with a straight face and not say a word while we were getting organized.

My mom and dad walked to the living room and I sensed that something was wrong. I could tell because of a quiet father meeting us at the door and the feeling in the room. I could feel it in my bones and when I went into the living room, I would find out what the disturbing news is. So I asked "what" and my dad said that my grandmother had died that afternoon.

I thought about the last time I had seen her, and that maybe I should tell her that I love her, because it could be too late afterwards, so I did and I was right. She also loved me because she told me that. I was happy to hear that and I know it would be too late later on. I could see how upset my dad was and I didn't blame him. My mom gave him a hug. It was decided that we would go ahead and attend the graduation and after that I couldn't think of anything except getting ready to go. I showered and let the nice warm waterfall all over me, especially my face. I took the shampoo and put some in my hair, and scrubbed my long thick hair. After I finished washing, I stepped out of the shower, gathered up my stuff and went to my room.

When I got to my room, I shut my door and locked it. I got dressed up in a long sleeved shirt and blue pants. Now by this time, my stomach was aching with nervousness quite a bit more than it was in the shower. The closer it got to my graduation, the more it filled my stomach with the pain. ; like a ship filling up with water and then sunk. I cleaned my face and shaved

Then I went down for supper, but I ate very lightly because I felt queasy and it wasn't getting any better. After supper we finished getting ready. Sometime before we left I asked my mom where the Tums were and I followed her into the kitchen. She took out the Tums from the cupboard and gave me some in a little bag.

I wanted my brother to come with us but he didn't want to because he was mad at me but I don't know what I did.

Sometime before we left, my mom phoned my friend's phone number and left a message on the answering machine, which is where the Autism probably came in because I should have done it myself, but I didn't. I was a bit stubborn I guess and I was very capable of doing so. Well, after everything was done we left. As we walked to the car, I noticed how nicely dressed we all were. The air was cool and the sky was filled with white clouds. Around the rim of all the clouds which were very well blended in with the blue

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sky, with the sunlight, which was very bright and in between, the light came down and was very clear. After we got in the car, I organized the Tums and took one, then put the bag in my pocket. I was so nervous, that my stomach felt like a dryer was turning, but at the same time, I was a bit excited.

We got to the school as quickly as possible and found a place to park. We then went across the circular drive and stood in front of an island of grass and bushes that stretched to the sidewalk separating it from the street.

I was wearing the graduation outfit that I didn't care for that much because it looked like a dress, but I wore it anyway. My mom was smiling but I didn't really smile. I squinted at the camera because the sun was too bright and it was shining in my eyes.

Soon, my mom's friend, Vicky, was with us and the dark blue clouds rolled over head with the sun still shining. While Amber and Vicky were looking at me, I was looking for Lori, but the only thing I saw was the parking lot getting full and little crowds of graduates here and there. I was worried because I couldn't find Lori and the closer it got to my graduation the more worried I got.

I knew that Lori could help me, but if she wasn't there she couldn't help me. My mom took a few more pictures, and by this time they convinced me to wear the square black hat. The only thing I could do now was to smile faintly and look for Lori. I was still popping Tums in my mouth.

After a couple of minutes we went in the entrance of the arena. We all went through a little hallway with blue material on both sides and stopped at the entrance of the big room where, over a hundred chairs were filled with people. I was even more nervous as I looked around and saw a few graduates on the other side of the arena. When I looked a few minutes later they weren't there.

Amber and Vicky went to sit down while my mom and dad and I went to find out where I was suppose to be. As we walked down a long hall I noticed doors on either side of me, some were open and some were closed. When we were half way down the hall, there was another hall going in the opposite direction, where we passed some other graduates. One of them had a white outfit and the others had black, like what I was wearing. As we continued, we got closer to the end of the hall where we saw all the graduates in their black and white outfits. There we walked right outside where most of the graduates were waiting.

The sky was white and still sunny. I was still looking for Lori, hoping that she'd be there, but I couldn't see her anywhere. I was nervous and being worried wasn't going to help, except make it worse. I still couldn't see Lori anywhere but when I looked in the parking lot, I saw a person getting out of a dark car and it looked like a friend of mine that I had hung around with at lunchtime the first two years that I was in P.C.

Some time went by and one of the principals got up on something and started to talk to the graduates. He spoke for two to three minutes and the second principal started calling the first two graduates to line up. He continued to call each of the graduates to line up two by two until we were all in line. When I was in my place, my mom and dad went inside. Even the teachers stood two by two. The line began to move and at the time that I was entering the arena, I looked all around and saw people on the left and right of me and I felt more nervous by the minute, but I walked with my head up. In a few more

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moments, all of the graduates were at their seats, and the staff was on the stage where their seats were.

The graduation music stopped and some time after, the national anthem was played. After the national anthem, everybody clapped and sat down. One of the principals opened the ceremony by saying what was going to happen. Somebody else came up and talked and then introduced the principals and the teachers. After that a graduate spoke about the achievements of the school and then addressed the graduates. Following that, two other staff members gave out plaques earned by some of the graduates.

While all of this was happening, I sat there patiently and mature adult-like, because this was a night to remember and I wanted to make it perfect. I was still quite nervous and it was building up inside me with a bunch of other positive emotions.

After all of the plaques were given out, and the photos were taken by the photographer, another principal announced awards to some of the other graduates. They too had their pictures taken, as well. One girl was called up to the mike and she, dressed in her white gown, gave a speech that was very nice and at the end she wished all of us luck. I felt happy but sad in a way.

Then, the principal stood and put out his hand with his palm facing up, raising it as a signal for the graduates to stand. The first row went to the stairs on the right side of the stage and when the principal called each name, the student went up, shook the vice principal's hand and held the diploma at the same time. AS this row finished, the next row went up. After we got our diploma we crossed the stage and went down on the left side of the stage.

Finally, when it was my row's turn to go up came I was filled with all the positive emotions which were locked up inside. Then, my name was called, and I went up and got my diploma, shook the principal's hand and went down the steps and followed my buddy to my seat and most of my pain was gone. After all the graduates had received their diplomas, we all stood up and we all threw our hats in the air, which happened to catch me off guard. I had no idea that was going to happen until did. Then seconds later we sat down and there was a lot of chatting going on.

The principal finished talking and two girls went on stage and sang a song. While they were singing all the graduates stood up and started to sway back and forth. I felt relieved from all that pressure and I felt free. I felt like I was going to cry and I was but I blinked to hold back the tears. Finally, the beautiful song was over and one of the principals went to the mike to thank a lot of people. She gave instructions as to what was going to h appear after the graduation and then all the teachers and principals stood up, went down the stairs and started to leave the arena, going past the graduates and then followed by the graduates. My row started to move and I followed my buddy into the aisle. We headed all the way to the back of the arena. As I was heading in the middle of the long aisle where a camera on a stand was placed, I saw my mom pop her head out of the crowd of people and then I saw my sister's head pop out a bit lower than my mom's. When I looked into their eyes, I saw tears of joy build up because my mom didn't think I would graduate. I also had tears building up in my eyes and the feeling of excitement and freedom. I felt like a big weight was lifted off my shoulders and then I knew why my sister made such a big deal about graduating because it was.

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While I was walking to the small hallway where I walked through when I entered the arena at the beginning, I felt proud, very happy and a bit sad because the graduation was all over. As I walked through the hallway I said thank you to my buddy, but she didn't hear me.

I finally got to the arena's lobby and it was crowded with a bunch of happy graduates. Everybody was talking and I politely pushed my way through the crowd to a less crowded area. I was looking around the lobby for about five to eight minutes before finding my mom on the opposite side of the lobby, I started politely pushing my way through the crowd once again and managed to get to my mom. When I looked up my family and Vicky were there. I went straight for my mom and put my arms around her. At the same time, I couldn't hold my feelings in anymore, so I put my eyes on her shoulder to dry off my eyes while I was crying. A few seconds went by and I lifted my head and stretched out my hand to Vicky, asking her for a Kleenex, but she put out her hand and gave me five. I shook my head "no" with tears in my eyes and a smile on my face. Vicky finally gave me a Kleenex and then my mom, sister, and Vicky started to laugh along with me. I took the Kleenex and wiped my eyes with it, then we went outside to the place where I had my picture taken before my graduation. My mom asked me something and I answered her then I showed her who my buddy was. She went over with me and thanked her and I also thanked her for helping me out. Then she reached up and I leaned down a bit for a hug. A second before she gave me a hug she told me congratulations and I told her the same thing. After talking and congratulating each other, my family, Vicky, and myself started to head for the road. At the road, we saw police cars and barricades that look like benches. The police cars had their blue and red lights flashing.

We crossed and went into the school. Just inside the entrance, was a wall that had a picture of each and every one of the graduates. The cafeteria was decorated for graduation as well. There was a section with black fabric in a rainbow form with tables filled with food and drinks. My mom and I found my name on the black fabric. It was on a white rectangle piece of paper and beside it, was the graduation hat. In black letters it said "congratulations"

I started looking for Lori again, but I ran into another friend that I knew the year before. It was Mrs. Blake-Cote. She was dressed in the same kind of clothes on that I saw earlier and it *was* the person that I saw getting out of the car before the graduation started. We both began to talk a bit. While we were talking, I continued to look for Lori.

Amber followed me while I was looking for Lori and then Amber saw her and told me. I headed toward her as fast as I could and she came to me at a normal speed and then we finally go to each other. We said "hi" and we gave each other a big hug. While we were talking she stretched out her hand to me and gave me a little bag. I gave Lori the card that I had in my hand. While I was talking to Lori, Amber asked me if I would like a drink and I said "sure". While she went to get me a drink, Lori and I talked and walked back to where my family was. We managed to get our way through the crowd and get to my family, where we talked some more.

Then, my friend came with her mom and I began to talk to her and then she gave me some flowers and I said "Thanks", with no change in tone, in my voice. After talking I had some pictures taken. I had one with my sister, Amber and both of us were smiling;

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another picture was with my friend. There was one picture with my mom, sister, and two friends. We were all smiling and my mom was practically laughing. Another picture was taken of me and part of my family, but this time it had Lori in it. There was a white wooden fence where we had some more pictures taken, the last one with Mrs. Blake-Cote.

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### **THE REST OF THE STORY**

I so wanted this book to be just Jeff's book, and having never even entertained writing/or helping to write a book was the last thing from my mind. I had hoped to fill in some of the blanks, but not to add so much. However, a very good friend and worker for Jeff read the manuscript and then we talked. Carrie warned me that readers need to know the rest of the story that only I know. I hope that in going back into the finer points, that we can give encouragement to those of you who are still struggling with professionals and yourself to help make a life for your loved one.

From the time that Jeff was three weeks old, I knew that something was not right. I didn't pretend to know what it was, but there had to be something. The struggles did in fact begin when Jeff developed colic and cried for such extended periods of time. I had no help with him as the only family was my husbands and they were unavailable to help me. From family and friends came criticism for the way I took care of Jeff and sometimes had laundry left in the basket. There was no way to put him on a schedule due to the crying. Then came the unexplained choking that later turned out to be seizure activity. Even then, because Jeff was so young, the neurological tests were all negative and didn't

show up until he was a few years older and the system was more developed.

I always attempted to make Jeff a normal child, but was unable to do so.

The screaming resulted in people staring at you as if you were some oddball, and as if you could do something about it. No matter where we went, life continued the same until we did find Dr. Rouses. She was the only support that we had.

My husband's mother was going through the illness and eventual death of her husband at the time Jeff was born, and my own family blamed me for Jeff's behavior. I was a bad mother.

I was told by my family that I should really spank him and show him who was in control and I was assured by my husband's family that there was nothing wrong with him. I did try spanking him, but soon realized that was not the answer and was left burdened with the feeling of guilt. There were several years when I disciplined him, either by the holding technique or putting him into his room, or depriving him of things like the TV. He never seemed to be able to retain the lesson, unlike the average child who learns from discipline. Jeff would return to his former behavior. And, this continued until he was going through puberty. It was if he wasn't able to remember or reason the purpose of the previous disciplinary event.

Jeff's rigidity was so marked in so many ways. It was a constant battle to try to keep up with him. With the aid of Dr. Roussos, we would brainstorm together until we developed a system of controlling or coping with the situation and maintain that until another arose. Then the process began again.

I must give examples of some of the things that have not been mentioned that are so indicative of Asperger's and neurological insufficiency and what we were experiencing. All of these were addressed to the professionals, but upon reading his medical chart years later, I realized that absolutely NONE of these points were mentioned. The doctors only continued to document that I was having trouble, and it was all with me. Jeff was OK!!!!

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When Jeff did begin to have words, he would only say them in my presence. He wouldn't even speak in my husband's presence for years.

I discovered that walking on the toes was a definite indication that there is some type of neurological damage. Jeff always wore out his shoes on the toes. I saved his early walkers, and they both have holes in the toe. I mentioned the constant profuse drooling before, and this continued until Jeff was a good bit older. I was unable to keep a dry bib or shirt on him for the first three years of his life.

When it came time for Jeff to dress himself, we met another challenge. When Jeff first started to school, I would taught Jeff that his socks were in one drawer and his underwear in another, etc. (Jeff wore the disposable diapers until he grew too big for them, then he had to wear just the underwear and change himself.) But Jeff would stay in his room for the longest time, and when it was time for him to go, he was still not getting dressed. Of course, my first thought was that he was just being resistant, but I eventually thought that perhaps he was unable to determine just what he had to wear.

I then began to put his clothes out the night before. He still did not get dressed and we continued with the last minute rushes to get him ready. I was trying to teach him what was developmentally normal at the time, what I should do and not to do for him.

Therefore, this became a very trying issue with us. Then again, I thought that perhaps Jeff didn't realize what order his clothing was to go on, as I had just been placing his them at random on the chair. So, I tried putting them in the order that they were to go on, and that was the last time Jeff was ever late for school or going through the last minute rush. He was always dressed ahead of time after that.

When Jeff was big enough he wanted a new red bicycle. We had purchased it for a birthday gift, and I brought it home that afternoon before Jeff came home from school. The neighbor boys across the street saw me bring the bike home unknown to me, and watched as I put it in the garage. As soon as Jeff got off the bus they came over quite excited and all talking to Jeff about his new bike at one time. Jeff smiled to see his new bike, but because the boys were surrounding him and making such a fuss, he wouldn't even try to get on it. He became so upset that I put the bike away, as he refused to try to ride it or even go near it until the following year.

Jeff was extremely awkward. He seemed to have difficulty with his fine motor skills. He wouldn't grasp with his full hand, but with his fingers only, and therefore was unable to get a firm grip on articles. Of course, this being the case, he broke many things. He continues to lift heavier objects in this manner, which results in much difficulty with this task. Jeff ran with a stiff uneven gate, although he was very fast.

For several years, Jeff's sister had to be awakened at night for medication, so, because of Jeff's constant incontinence; we would take him to the toilet at that time. I noticed that Jeff was so very very rigid when we got him up. He would stand at the toilet with his legs and arms straight and rigid. His fingers would be spread and rigid as well. This was never explained to me and again I feel that it was neurologically based. It was just too strange and obviously not normal. A very sleepy child will be limp instead of stiff.

It wasn't until Jeff began his first grade in public school that the teacher recognized that he was having seizure activity. There was an abnormality identified by EEG. Jeff was medicated for approximately five years. He experienced petite mal seizures, which

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usually began with the choking, which I mentioned earlier in the book. Then he would just freeze for a short time, and continue with what he was doing. Only one time did I see Jeff experience an aura before a seizure and at that time, he was talking to a voice that he had heard, but not mine.

Jeff continued to present the crying and screaming for several years. Jeff, in his 'tantrums,' put many holes in the walls. He never intentionally hurt a person, but as his now says, the walls in the house frequently looked like Swiss cheese. He put holes in walls and doors faster than we could repair them.

Social services and other agencies were brought into the picture to teach us how to work with Jeff. We had several workers who soon got stuck and then another would come in. One lady came twice, and Jeff went under the dining room table. She spent an hour trying to get him to come out but he refused. After the second time, it was decided that a man, especially a big one, would be able to deal with him. Jeff locked himself in the bathroom so the worker thought that if he called the police, Jeff would be scared enough to come out. If it hadn't been so tragic, the sight of two big police officers and a big social worker trying to coax, threaten, and bribe a not so large boy out of the bathroom. They ended up taking the door off in order to get to him.

Another tragic funny was when this same worker told me in the end that when Jeff acted up and needed disciplining, for me to pick him up and take him to his room and lock the door until he calmed down. He was taller than myself and he was too big for me to hold and carry up a flight of stairs. All I could think was, I'm going to pick up this hysterical child who was bigger than myself and carry him up a steep flight of stairs, put him in his room, then lock the door. I asked the worker how I was to accomplish this. Jeff's rigidity was such that even the slightest expected compromise would set him off into a tantrum. If there was to be a change, it had to be presented well in advance, repeated several times, and extremely detailed. This would give Jeff the time to internalize the needed information in order to make the necessary change.

One evening, Jeff was watching TV and for Jeff a program was not over until all of the credits had finished. In those days, even the regular weekly shows ran the credits following the presentation. Jeff was told that he could watch the 9:00- 10:00 p.m. show but he would have to go to bed following it. When it ended, Jeff's dad told him to turn off the TV and go to bed. He seemed to ignore his dad, and continued to watch the credits. Ron went in saying that his show was over and turned the TV off.

Jeff began screaming saying that his show was not finished yet and tried to turn the set back on. His dad turned it off again; Jeff became quite hysterical. Ron picked him up and took him upstairs to his room and locked him in as we were previously instructed to do.

While this was taking place, I was on the phone learning that my sister had been diagnosed with bone cancer that day. I looked up to see two or three police cars on the street and police officers were coming toward the house. Naturally I was very upset over my sister and I realized something was wrong here as well. As it turned out, after Jeff had been put in his room, he started screaming out his window "Mommy help me." A passer-by had heard his screams and called the police.

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Naturally this led to an investigation. This was after Jeff had been in the psychiatric unit of the hospital and before we got a diagnosis. The professionals were again telling us that Jeff had been cured of his mutism, and there was nothing else wrong with him except oppositional behavior.

Upon learning that we were trying to deal with a very difficult child and at this point had exhausted all of our resources in an attempt to get help, one of the police officers suggested that instead of trying to deal with him by ourselves, that we call the police ourselves every time he acted out. She had a sister who worked with youth protection and advised this in order to draw attention to our desperate need for real help.

This I did, which ended us back in the Montreal Children's Hospital emergency room. I phoned our social worker that met us there. We were referred to a psychiatrist, whom we met on a beautiful Saturday afternoon. After a few minutes with us, he decided that Ron was beating me, and Jeff's behaviors were to protect me by keeping the attention on him. In coming to this decision, he instilled fear into the other children by his implications and questions. They left there confused and thinking that their dad could be beating up their mother.

I was able to convince him that there may be some truth to the fact that Jeff did in fact suffer from some neurological manifestations and he did refer us to a neurologist, I believe to satisfy me. He also referred us to the outpatient clinic where Jeff was seen one time, and he was to be placed in a socialization group held at the clinic weekly. We didn't hear from them for quite some time, and eventually when I phoned back, they had forgotten about Jeff and the group had ended. They then actually put together a rather lame group activity, which didn't last long.

At this point, I had the opportunity to read material on Autism and was convinced that Jeff had this condition. The neurologist asked me if Jeff had ever had a CT Scan and I told him that I didn't think so, but I wasn't sure. He ordered one to be done and then preceded to do some testing himself. He got Jeff started and left us alone for quite some time. When he returned, Jeff had completed what he was instructed to do, however, with much struggling. Had the doctor remained in the room, he would have been able to observe this and would have realized that a true problem existed.

When I went back to him, he accused me of lying to him; saying that I told him that Jeff had never had a CT Scan. Being called a liar, I lost it and told him what I thought of his way of handling our situation. We ended up yelling at each other.

Having familiarized myself with Autism, Jeff at that time presented 12 of the 16 characteristics required for diagnosis. So off I went again to the Neurologic section of the Royal Victoria Hospital and asked them to see Jeff. Their findings were that because Jeff had played baseball the previous summer he couldn't possibly have Autism, and that was that.

After that, attending a meeting with the social worker, she indicated that she was unable to help us. At this meeting, she asked the children to leave the room and stated that the root of the problem with Jeff must be our sexual relationship since the professionals could find nothing else to cause our problems. With that, we never went back to a social worker or agency again, realizing that they were grasping at straws to find an answer. I just decided that there was nothing else that I could try and that from then on, I would only respond to people who approached me on Jeff's behaviors. **I QUIT!!!**

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Another interesting behavior of Jeff's in the rigidity/ inability to change area was in his clothing. When Jeff was young and it was 'cool' to wear sweat pants to school, Jeff wore them. But when it was no longer 'cool', and jeans were the in thing, I had a very difficult time in getting him to wear them. He refused for months before I could finally get him into jeans, and I really don't remember how I managed that unless it came with the season changes. It was always difficult to go from winter to summer clothing and vice versa. He would wear the winter clothing and shoes until he became so extremely hot and miserable that he would finally agree to wear sandals or shorts and short-sleeved shirts. When he first went into the hospital for the five-month period, he was wearing heavy boot shoes and refused to change them. The nurse actually called me in to see if I could get him to change. The problem was that his feet were perspiring so profusely that the odor was terribly offensive, and they were unable to get him to go to lighter weight shoes. I always got a chuckle when this occurred because it give the professionals a minute glimpse of what life was like in our world.

Jeff continues to have these little quirks about wearing apparel. When I buy him shirts or clothing, he will frequently designate where and when it will be worn. It is next to impossible to convince him to wear that piece of clothing for any other occasion. He has shirts that are strictly for church wear and some for his presentations and others for everyday wear. There is no way he would wear his church shirt for a presentation, or otherwise.

When Jeff was to go to Pierrefonds Comprehensive High School from ST. Thomas, the people at St. Thomas highly recommended a specific program which was suppose to be perfect for him.

In the fall when Jeff started, the program turned out to be quite different from what I thought it was. Jeff was placed in a classroom situation with students who had no type of learning disabilities and he became lost from the very beginning. I knew that he was over his head, but I refused to get involved and start something again. It wasn't two weeks into the school year when the phone rang and the teacher, sounding very distraught, apologetically began to tell me the difficulties they were having and that "this is just not the program for Jeff." She was surprised when I laughed and said, "I know." It was then decided that Jeff be placed in the self contained classroom. Here the focus would be on Jeff's socialization rather than academics.

In a couple of months, his teacher in this classroom, had much experience with people having Autism, and phoned me one evening to ask what Jeff's diagnosis was. I then told her that there wasn't one, but that I believed that he had Autism. She agreed with me and with the explanation that nobody seemed to be able le to give us one, she referred us to somebody who could help. We were then directed to a psychologist whose life's career was working with kids with Autism, and within a week, we learned that he not only had Autism, but distinctly Asperger's Syndrome.

From there, Jeff's life really soared upward. He began changing in that he had been seeing himself as a 'bad' kid. Now he knew that he wasn't a bad kid, but a person who had a condition that controlled him. He became happier and took the responsibility to start working on controlling himself.

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It had been said that a diagnosis didn't matter for a person like Jeff, but indeed it does. We now had something to work with and to work on.

Jeff was able to get his driver's license. It took 6 long years, a lot of repetition, visits to doctors, again, to get a medical approval, and most of all, a kind, wonderful woman, Robyn, who gave Jeff the attention and help he needed to become a good conscientious driver. Robyn even took Jeff with her when she bought a new car for the driving school, and they named it, what else? JEFF!!!

April 2002

Today, Jeff is doing public speaking about himself. He love is working with children and families who are involved with Autism/Asperger's Syndrome. He is presently working toward moving into an apartment on his own or with a roommate. He desperately wants to become independent. One of his greatest wishes yet is to make friends on his own. He just recently has made three new friends and one of my happiest moments was when Jeff didn't come home one Friday night and not at all until late Sunday evening. He had been hanging out with his new friends.

It is so wonderful to see Jeff growing and meeting the goals that he has reached in his life. And as one who has been with him all along the journey, I am so very proud of him, of his perseverance, his determination, and his courage. I am so very thankful for the blessing of being given the responsibility and the experience that God gave me. It has helped me to know what is truly important in life and there is no greater rewards than seeing her children become happy responsible human beings.

# *A RAGING SILENCE*

## **No One Understands**

### **THIS THING CALLED AUTISM--WHAT IS IT REALLY?**

*By Amber Foreman*

It's patience, perseverance, laughter, tears, daily surprises, understanding, frustration, and most of all, loving.

#### **METRO:**

Do you ever take the bus down town and transfer to the metro? Autism runs madly to the transfer machine, which quickly spits out 25 transfers for him. These in turn are handed to you with a smile. You politely take them, discreetly placing them in your pocket with a smile and a nod hoping no one saw

#### **NEAT FREAK:**

The "neat freak" that thinks his room is cluttered, decides to clean it. Out goes everything except for what he thinks is necessary for living. By the next morning his room is clean and you can't get out of yours, because his idea of cleaning is putting his junk in the hall in front of your door. So you can't get out!!

#### **THE LIGHTS OFF:**

Autism is the environmentalist and conserve of energy. During a commercial, you leave your room to get a quick snack. Upon your return thirty seconds later, you find the TV off, lights off and no one in sight.

#### **TRIPS:**

Then there's getting ready for a long trip, which involves a lot of packing. Autism is waiting impatiently in the car at least an hour before you're ready to leave. And before you can get to the T-Can, he's already saying "Are we there yet?" OR "I have to go to the bathroom.

#### **FAN CLUB/BEST FRIEND:**

Autism is your best fan club. He's always agreeing with what you say. After everything you say, you hear, "yeah, yeah, yeah!" Since making friends is next to impossible for autism, his best friend is a budgie named "Chipy" Although Chipy does not respond, except for the occasional squawk; endless conversations are carried on between the two of them.

#### **FASHION SHOW:**

Autism does appreciate the finer things in life. At the fashion show the favorite scenes were the short shorts and of course the lingerie.

## ***A RAGING SILENCE*** **No One Understands**

### **GIRLS DAY OUT**

Then this is “Girls day out” At least that’s what is use to be. Autism in his rigidity, would only go to Mickey D’s, most of the time refusing to go out at all. Then came the day when he was so bored he came with us. With his new adventure, to his surprise and ours, he discovered new food and a new restaurant. Since that day, when preparing for our “girls day out” all we hear is “are you going to eat?” What happened to girls’ day out? IT WAS GOOD WHILE IT LASTED!!!

### **FAMILY IN TROUBLE:**

If one of the family members is in trouble, autism is the first one there ready to do what ever it takes to protect them

### **LA RONDE:**

Then there’s when I was asked by my mother to take him with my friends and me to LaRonde. Having him standing right there made it hard to say “no”. Talk about embarrassing! Here we are, my friends and I walking through LaRonde with him following us with socks pulled up to his knees and jeans cut off to the knees asking if we could ride the bumper cars.....AGAIN!

### **THUMPER:**

I know autism as “Thumper.” Have you ever heard a size 15 feet on the stairs while you’re trying to sleep?

### **GETTING TO KNOW HIM:**

Getting to know the real Autism, “Thumper” today means joy. It’s the smile I see after he has helped another special needs child. It’s the growing self -esteem that I see in his face and the love in his eyes that shines when he knows his life has truly made a difference.