

A New Me: Living Without Labels is Macena Lenora Mason's powerful autobiography of perseverance and transformation. She turns others' doubts into positivity and accomplishments inviting readers to rethink ability and believe in possibility.

A New Me: Living Without Labels

by Macena Mason

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A New Me: Living Without Labels



Macena Lenora Mason

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Over the years, trips have become difficult with my family, especially my father. My father doesn't understand how the medicine I take can affect my body, making it difficult to do a lot of physical activity without taking rest breaks. Because of my quick exhaustion, I have to take more rest breaks than normal people to keep from becoming sick. It has become disappointing that I cannot do a lot of things with my father just to keep from having the arguments, as well as the bad feelings about this disorder and myself. It's hard to look at myself sometimes and see one image and mentally know that I am something else on the inside. I can look fine on the outside, but feel really drained and tired on the inside.

Family engagements, whether on my mother's or father's side of the family, have never been the greatest. It has always been very lonely for me. I never knew how to speak to any of them and, when I would try, I would not get any response back. Seeing relatives conversing with other relatives is very hard. I felt left out because I did not grow up with anyone, like a brother, sister, or even cousins around me, though my mother and father did. Growing up with relatives your own age would have made me a stronger person. Growing up alone tends to make you feel emotionally weak inside because, every time I would see those people, I felt alone, just as I was in school.

So, I grew to feel envious of what I saw. It pushed me to want to make my own personal family of friends to fill the big gap that had been left in my heart. You can make your new family big or small to fill the gap. I started out as a very sensitive, closed, and hidden person while I was maturing. You may also still have a small hole in your mind and heart for your family. There are times when I still do.

Learning On My Own: Setting Goals

When I was 13 years old, I started noticing that other children could do things that I couldn't. Those were things that I thought only adults did, or that adults taught you when you were old enough. For example, you learn how to walk by the time you are at least two, not ten years old! I started noticing that there were children out in the world, children my age, who were already doing a lot of adult things. It was bad enough that, as a child, I couldn't fight for myself. No, I wasn't a strong child growing up. So, when I saw that those same children, especially the ones who gave me trouble in school every day, could do these things, then I wanted to do them, too.

What really pushed my nerve button, or made me mad, was that those kids looked like me. They were black kids also. Those black kids were probably from Washington, DC, and coming over into my area, Lanham, MD. It made me angry inside to see that.

The only thing I needed, though, was the support at home to do what I wanted to do, which was to learn how to ride the Metro bus and to grow into a young woman. My mom was older, and I knew that one day she would have to let me be independent, to make my own choices and decisions. One of those choices was learning to catch the Metro bus by myself.

One day, she was going to have to leave me alone, let me do things for myself, and allow me to make my own choices and decisions. Choices like riding the Metro bus.

One day, I got my nerves together and stood up to my grandmother. For me, that was very difficult, especially when you have always loved someone all of your life, and someone who, to you, looks physically bigger than you. Maybe their voice has

always sounded stronger than yours. So, while she was sitting down, I took my time and let out my feelings. I told her how I had felt, and that she had to start letting me grow up to do the things that I wanted to do so that I could learn on my own like everyone else. Emotionally, all of that was difficult. For the first time, I was standing up to my grandmother and it felt weird.

She didn't want to let go, and it has taken a lot of time. Whether she agreed to it or not, I still went ahead with what I wanted to do, which was to grow up. Afterwards, I found that other people may have looked at and seen me differently from a lack of understanding my goals, accomplishments, and illness. From an aunt, I found out that my cousins in my family didn't like me because of what I had done, or was able to do. It wasn't my fault. I couldn't help that I was an only child. I also couldn't help the time period during which I was born, or the person to whom I was born.

The condition that I have helped me to make better choices because it had already pulled my life down from the very beginning. I didn't want to be pulled down any more than what I had been, so I tried my best to love everyone. Yet, everyone couldn't see and love me in the same ways that I had loved them. I fight with this feeling every time I see my family. That is why I say that there are only a few people in my family that I have been allowed to speak to. One is my uncle on my mother's side.

When my mother chose him to be my godfather, I believe she made a very good decision. Believe it or not, he actually gets mad if he doesn't hear from me in a long time. My problem was that T was too scared to call. I would always guess that he would be too busy to speak because most people that I have ever tried to speak to never had the time to speak to me.

The other person is my other uncle on my father's side. He is also emotionally nice as well. I can speak to him about our family as well. He was the only one, when I was little, who acted as if he were my friend, and not just my uncle. Over time, my trust in him built up as well.

I have spent time over the years doing different activities. I would do those different things to help teach myself and help myself with my social skills. Growing up, I was a shy child. A shy child meant that I was a very quiet child. That made socializing in school, with family, and other outside places difficult. It was bad enough that I spoke with a slow mind and still do. It doesn't mean that I am stupid, just slower. It takes me longer to verbalize my thoughts. Because there were social things that I didn't know how to do as well, I took my summer, starting at the age of 14, and used it to practice my social skills.

Since I had no friends to socialize with on a daily basis, I would go to the pool every day during the summer and practice speaking to people there. That was one of my social skills goals that I couldn't work on very well at school. So, I worked on it during the summer at the pool.

Another goal that I had, which I also worked on at the pool, was my swimming. Believe it or not, I was afraid of the water. My mother would put me into summer camp when I was little and they would try to teach me how to swim by holding me in the water. I was afraid of swimming because I thought that those people would drop me. I didn't know them well enough to trust them to hold me in the water. So, at 14, I took the time to read an encyclopedia about swimming and learned how to swim.

When I went to the pool every day, I would practice swimming to the wall of the pool to make me feel safe. I would do whatever the encyclopedia told me to. I then took up swimming lessons to build up my skill some more, after my confidence was built up enough. Now, I can swim into at least five feet of water. I can float and swim on my back a little. The most I have to learn now is the treading part for the eight feet or deeper water. Nonetheless, I can get in the water and still have fun like other people.

When I was 15 and 16 years old, I worked on other social skills as well. Those also helped me to speak to people and helped me to learn about myself and what I could do for other people.

By that time during the summer, I began volunteer work.

The first two places that I volunteered at were in hospitals. That, for me, felt like a real job even though I didn't get paid, and I enjoyed it a lot. I always hated the fact that I had to leave to go back to school. Since then, I have volunteered in other places, such as the American Red Cross. Doing those things teach me how to work with others. They have also taught me the best things about myself as a person. For example, I know that kids love me. I am more patient with kids than some other adults might be.

Throughout my life, I have spent time doing other activities as well. Some of those activities I did for only a short period of time, while others I did on and off. Some were playing games like t-ball when I was about seven years old and taking ballet lessons between the ages of 14 and 16. I have also taken courses and classes in things like Barbizon and H & R Block. I have done those things to keep active, to see what it is that I can do, and to

find ways to meet other people. Job wise, it also helps me to see how far I can go mentally without stressing myself out and still enjoy the pleasure of working like everyone else.

One of the best experiences of my life was the chance to learn how to be on my own without my family. That experience was unexpected. I didn't even plan for that experience to come when it did. I was grateful to God for the experience when I had the chance to do it. Through high school, one of my teachers had put my name in for the chance to go to Russia. When I heard about that, I was surprised. It was unexpected that anyone would have thought about me or remembered me while going to that school. I didn't feel like anyone cared about me at all, teachers, students, or counselors alike.

I told my mother and she gave me the okay to go on the trip. The only thing needed was the money, which was a lot. Since it was my trip, I went to my family church. I used my music ability, and my family, to raise money to help me to go on that trip. After the program, when I was home, I read the cards and counted the money. I then sent thank you cards to everyone in return.

Years later, I found out that my grandmother had secretly given me a lot of money in order for me to go on the trip. Instead of that making me feel happy, it made me feel angry because I felt that I couldn't thank her in the same way as everyone else. To me, my grandmother had been too proud to tell me during the time of the event and had waited until during an argument to tell me. So, if she had to wait that long to tell me, to show her that I was growing up, I wouldn't thank her, but not because I didn't want to. I wanted my grandmother to stop being so proud, and acting as if I couldn't handle information.

Through that whole experience, I again had a chance to work on my social skills. I met a lot of other kids my age. During orientation time, I had the chance to meet special people and go to special places. I went to the Capitol and met Senator Paul Sarbarnes. We also had a tour, learning about the history of Washington, DC. The next day, we then left to go to Russia. I went on my first trip out of the country for the chance to prove to my family that, even with my condition, I could still take care of myself without them.

Having the chance to go on the three-week trip to Russia was an adventure for me. That trip made me feel like a "big-little" person in one. I felt "big" because I had this big title with my name as well, Student Ambassador of the United States. It made you feel like those old people that you see all the time on the news coming to see the President of the United States. More importantly, I felt "big" because I was away from my family for the first time. This was even the first time that I had been on a plane.

A Surprise Turns Into a Dream

While in Moscow, we went on a tour where we took a lot of pictures. Experiences also occurred with the Black Market where people would come up to you and sell things that usually weren't good for you. While there, we visited the Lenin Mausoleum, which was worshiped like a religion. There, we stayed at the Molodehmaya Hotel for one night.

In Moscow, we also went to the Moscow Kremlin where a group of churches was set in a square. After that visit, we went back to

the hotel. While at the hotel, I took a nap and, later that day, we left on the train to go to Leningrad, our next stop.

On July 23, 1990, we arrived in Leningrad after a very nice train ride. In Leningrad, the experience was the opposite of the experience in Moscow. The food was better but the tour in Leningrad wasn't as good as the one in Moscow.

The sites in Leningrad that we saw during the tour were very sad.

However, we went to see *Swan Lake*, a ballet production, at the theater on the next day, July 24, 1990. We went on a tour to the Petrodvocets (which is another name for Peter's Place). When we toured Peter's Place, we had to wear foot covers to protect the floor because everything was kept in perfect condition.

We visited a place to see where Russian music was made and, while there, I had a chance to play on their grand piano. The rest of the day was spent relaxing with some of the people I met on the trip.

On July 25, 1990, the day was spent relaxing. After breakfast, time was spent looking for gifts to take back home. That afternoon, we went to a museum called the Heritage, which had a lot of pictures in it. After going to the museum, we went back to the hotel, ate dinner, and prepared to go to a social event. At the social, I was able to give out some of the gifts I had from the United States, which we were told to bring with us.

While there, I received a gift from a Soviet named Caiiu. I had a nice time talking to Caiiu, despite the language barrier, He was a very nice person and I tried to teach him the electric slide. In return, he gave me one of their musical instruments.

Our next stay was spent at Novgorad on July 26, 1990. Getting there was difficult because the bus was not working correctly. Once we arrived in Novgorad, the day was spent getting settled. The rooms in the hotel were so nice that they made you feel like you were at home. My stay in Novgorad wasn't as nice as it could have been because I had a lot of seizure attacks, which caused me to feel tired, and then unable to eat.

While there, a tour was taken of Novgorad where we saw very pretty churches. A visit was also made to the Yurien Monastery. After lunch, we attended a nice concert and the rest of day was spent resting.

The next day, July 28, 1990, wasn't very exciting. A drive was taken to see a bell factory early in the morning. The visit wasn't what was expected. There was nothing in it that pertained to bells; in fact the building was a shuttered factory. During the ride, a majority of us slept on the way. Later, time was spent shopping and I was able to find gifts for my family. Later in the day, we took a boat ride. The scenery during this boat ride wasn't great, which made it very boring.

That evening, we went to a Russian disco during our free time. You can picture a Russian disco as an American disco. The difference is that their disco is held outside where there was a very bad scent. This scent carried everyone's body odor as if it were in a closed room.

The next day, while still in Novgorad, was a very slow-moving day. We spent the morning sleeping in. In the afternoon, we went to the Kremlin. Afterwards, time was spent getting ready for our departure to Kalinin.

On July 30, 1990, we left. When we arrived, we ate lunch in Vyshni Volockok, which had some nice food. I wasn't feeling well because the day before, I had eaten food that made me feel sick. Lately, I haven't eaten any fresh vegetables. During our stay in Kalinin, we met really nice people who greeted us on the bus.

A Chosen Moment: Meeting My Host Family

We were also greeted by our host families. In my host family, the mother's name was Demaia, the father's name was Victor, the grandmother's name was Nastia, the sister's name was Olga, and they had a daughter named Tamara. After meeting them, we were greeted by the mayor of Kalinin with bread and salt.

After meeting the mayor, I left to stay with my host family. We left with a crazy, fast-driving cab driver. My host family had a beautiful house in the country. They were a very nice family. It made them feel really good when we tried to speak in their Russian language.

One of the ladies who went with us on the trip came with me. Her name was Miss Holland. A grand meal was made for us when we (Miss Holland and I) arrived at their house. The host family takes it very personally if you don't eat a lot of the food made for you.

After dinner, a walk was taken around the village, which had a lot of rocks in it. Being with the host family made me feel as if I was at home. My host family had two homes. The other home was a flat in the city. We went there the next day.

On July 31, 1990, my host family took us on a ride on a Russian bus. That was the first time I had ever been on one. We went to

a local museum, which showed old teapots like some of the ones my grandmother used. I also saw really old cloth, and how the clothes were made. We were also shown how people lived in a model-type home that was built in the museum. Afterwards, we spent time again in stores where I was able to find some more souvenirs. I also started to spend more of their Russian money (which wouldn't be any good to me at home, except as a souvenir).

We ate lunch at the Volga restaurant later on, where some of my friends were staying. We then took a boat ride to my family's flat. We also had to ride another crazy taxi on a crazy street, which made you feel as if you were going to die. Afterwards, I spent the rest of the day relaxing because I felt really tired. Everyone else spent time doing another activity that evening. I was too tired to participate. On August 1, 1990, my breakfast was eaten with the host family.

Since there was free time open, it was spent going into town to shop. Later, a tour was taken of the city. Lunch was eaten at a hotel where they usually had meat and potatoes. Everyone in our group was getting sick of eating the same food constantly. After lunch, our group visited a church that happened to be stuffy. We were allowed to ask the priest questions. I, personally, didn't stay in the church very long because it was too stuffy for me.

After the visit to the church, Miss Holland and I went back to have dinner with the host family.

A day of sadness came for me on August 2, 1990. It was the last full day with my very nice host family. The stay was a very nice, fun, and exciting experience. On that day, a tour was held of

some very small sights in Kalinin. We also had been learning new Russian words. An example of a Russian word is "Ducha," which means a group of houses that are in the country.

That evening, a fun time came that made the day seem better. Later in the evening, a picnic was held in the woods with our host families if you were lucky to have the chance to stay with one. This was a chance to say goodbye. Conversations and gift-giving were held with our families. They had given us gifts and, in return, we did the same. I received pictures of them as a gift. I also received a Russian flag from them.

August 3, 1990 signified the last meal with my host family. The breakfast was very quiet. The father of the home went to get Miss Holland and me a cab. When you think about the cab drivers over there, you think fast. Then, we had another fast ride with a cab driver. This particular one had to dodge some dogs in the middle of the road by driving on the curb. When we arrived back to meet everyone else, we settled on a bus that took us to visit a local television studio. There, we answered questions about our stay and our thoughts on Kalinin. I answered one of the questions because it related to staying with a host family. After the tour of the television studio, we went back to the hotel. We then ate lunch before getting ready to leave for home.

On the bus, I spent time catching up on my writing and reading. On our trip back to Moscow, I spent time sleeping. Everyone else also spent time sleeping on the trip back to Moscow. When we arrived in Moscow, we stayed at the same hotel—the Molodezhmaya Hotel—where we'd stayed when we arrived in the USSR. We ate dinner at the hotel. The dinner was great, even though others didn't think so.

That ended our day going to our last city.

On August 4, 1990, breakfast wasn't satisfying to me. I also didn't feel like eating a lot of food. While in Moscow, we visited a Novodevicki Convent, which wasn't satisfying to most of us in the group. Things started to look alike. In that same area, we went to the Beriozka Shop. The items in the shop were costly. It made us feel upset that we would have to pay a lot for the items. Later on, we had lunch in the Arbat area, and a tour. Time was spent in the Arbat area buying items to help us to get rid of our rubles. (Rubles are the Russian form of money.) We needed to get rid of them because we could not get them changed back to American money.

It's very hard to spend and get rid of Russian money, especially if items are very high priced. The Russians will take our American money but have no way of giving it back if you are leaving.

After dinner, we went to a Moscow Circus. When compared to an American Circus, it may not look as good. If you forget about America and its circus, it doesn't look bad if you go with the intention of experiencing something new. I looked at the circus as if I lived in Moscow. This helped make the circus really nice to see.

On August 5, 1990, an experience that was supposed to take place didn't. We were to go to a student camp, but had gotten lost. Directions were asked of a policeman who told us that we would run into a military installation camp, and could get arrested. So, a long trip of 60 miles was wasted.

After lunch, some people went to a museum or to the Beriozka Shop for a few minutes. After returning, we had free time that was spent playing cards.

That evening, we ate dinner at the hotel before we left to go to a café. At the café, we socialized with some more Soviets. I expected the people to be my age, but they were older.

When we went back to the hotel, I spent the rest of the day writing and talking to Miss Cassidy and Mrs. Hayes, who were two other teachers on the trip.

August 6, 1990 was our last full day in Moscow, Russia. We went to Arbat Street again to spend more money shopping. During the day, the heat had gotten to me and caused me to have more seizures. I received help from those I'd become close to in my group.

I was then taken to the hotel where I went to my room to lie down. Everyone else went to eat lunch, but I wasn't able to eat. During that time, I spent it taking a nap for a while. When I woke up, I spent the time packing my luggage and gifts that I had put names on. When dinnertime came, I was able to eat. I had a very big appetite.

The rest of the time, I spent resting and writing in my book. Our group was feeling a lot of emotions. The time was drawing near for us to get ready to go back home to the United States.

The day called the Last Day finally arrived. We left on August 7, 1990. To be on time for our plane ride, we woke up at 4:00 a.m. That didn't help at all. We still didn't get out on time. We were the second bus to get on Aeroflat, which is a really small plane that

is very hard to move around in. The comfort of a Russian plane is not the same as the comfort of an American plane.

After our flight to Germany, we were checked out again. I personally had scissors in my bag that would make traveling for me difficult. The scissors had to be packed separately from me, and I was to receive them later in New York. We also had other problems as well. There was a layover and a missing child, which caused us to wait at the airport longer than we expected. While at the airport, we also had a quick lunch.

After some time, we were able to get on the plane to New York, heading for John F. Kennedy Airport.

That ended my whole experience, which was a surprise to me. I was able to see other parts of the world and experience life differently for myself. I had also received Soviet pins from people that I had met as souvenirs for visiting their country. Pictures were also taken of the nice places that I had visited during my stay in Russia. I had fun times with those I had met in my group, whether it was during one of the activities, or the relaxing times we had together, doing things like playing cards.

Personally, I learned through that trip that I would be able to take care of myself despite my condition. It gave me the chance to see and live life in a different way. That trip gave me a surprise that I had never really focused on for myself. The most special thing that the surprise gave to me was where it led. That surprise led to my dream.

THE DREAM WAS "MY PROM"

My trip to Russia gave me a way to fulfill my dream of going to my prom. I was a person who didn't have many friends. I didn't have the connections that most girls had in knowing someone who would like to take them to their prom. If I were to go, I would have been going by myself, or not at all. However, due to my trip, I was brought into contact with other students.

It was then time for my dream to come true. That dream, you could say, was second in line with getting married. I didn't forget that day.

The only people who I knew at that time were those that I had just met from going on my trip to Russia. I was scared when I took that chance. I took the list of names and dialed the first guy on the list. His name was Carlos. I was nervous when I picked up the telephone to call him. I had also pictured myself having to dial every guy on the list. Thank God I didn't have to do that. God had made my date the first name on the list!

When I called, I was lucky that Carlos was home. I asked him if he would escort me to my prom, which was to be held on May 17, 1991. I was surprised when Carlos said, "Yes." Personally, I wasn't expecting much from him. I was just so happy to have someone to escort me.

Before the prom, I went shopping with my mother. I purchased an emerald, green dress with matching shoes and diamonds. (The emerald is my birthstone.) Just before the day of the prom, I had my hair and nails done.

On the day of the prom, Carlos arrived and, to my surprise, he came with a limousine. I was astonished to see the limousine.

The way that I felt, you could have taken me in anything. I didn't see myself as that special. That is how he made me feel. I felt like a special girl on a special night. You could have matched my emotions up with those of Cinderella. He also had a corsage for me. When we arrived at the prom, those in my class were surprised by the nice guy I had with me. They probably didn't think that I would have anyone with me at all, judging by the expressions on their faces.

At the prom, we danced and took pictures as well. (The picture sits out in the living room and, every time that I see it, I admire it.) That day, attending the prom, was the end of a bad past, and the beginning of a good future.

When I went to high school, except for the trip to Russia, those were the worst four years of my life. Nobody in my family, I believe, had any faith in me. Even if you talk to some of them today, seven or more years later, they still say the same things. I went to an all-girl high school. Every year, I hoped for the same things and believed they would happen. I wanted, of course, good grades, friends, my emotional pain to stop, and—most of all—for the seizures to stop. I may have gotten decent grades, but nothing else would follow through for me. Things just got worse.

At St. Ann's High School, the homework was tough. People I knew did not have conversations with me. They did not understand why I would do so much homework. The homework at that school kept me up studying until 10:00, sometimes 11:00 p.m. My school gave out that much work. Our school had a nine-period day. Three of the periods were lunch, study hall, and gym. Having a seizure disorder made it difficult to hold in information like the average person. I had to study far in advance. I could not

study everything in one night, as most people do, because it would just make me nervous, and stress me out even more. So, I just put up with it and planned my time out well to get through it all.

The teachers in the school were difficult. I had to find ways to get around them because sometimes they acted as if they did not want to answer your question. There are teachers who will make you question your grades. Music class was an example because the teacher had to go by personal judgment. Music was a class that did not give homework or tests.

My emotions seemed affected because I still could not get what I wanted. I wanted the teasing to stop, and to have some friends in my class like everyone else. I still could not win because people continued to tease me. When I had gym with my classmates, it became a lot worse than when I was in grade school. I thought that I could have a better chance, at least with those who did not know me that well, but that did not happen at all. The only time that I could make any friends was during my lunch period, with students who were not in my class. I was still miserable inside because I had to be around those who were in my class a lot more.

Physically, that was a stressful time as well. I was praying a lot during that time for my seizures to stop. But, in fact, I have them more often. I would have them at school, on the bus, or just anywhere.

Nobody in my family believed that I could do anything with the disorder. Some were even against me attending a private or Catholic school. My family saw how hard I would work and that

it would cause me to have seizures, maybe because of physical stress.

All I wanted at the time was for my doctors to make the seizures stop.

It was just important to me that I finish no matter how it made me feel. If it meant that, for years, I lived on six to seven hours of sleep, five days a week, then that was what I did.

I have never received a 3.0, much less a 4.0 average. However, through it all, I still learned something because it prepared me for my college life. It made me feel mentally strong inside. When I got to college, my first goal was to plan out my schedule to fit my mental, emotional, and physical life. While I was in St. Ann's, I had no choice but to do what others told me to do.

THE BEST TIME OF MY LIFE (COLLEGE)

During my time in college, I was able to live a different life. That life allowed me to feel like a totally different person. I could put my past emotions behind and become a totally different Macena. Whoever I was before, I felt no longer existed. I had small experiences that seemed big because I had never experienced them before, experiences that gave people the chance to relate with each other.

The most special experience for me was just making friends. That had been the hardest trial that I could ever accomplish. While in college, I was able to have friendships with people by joining clubs. That led to me being able to learn, feel, and know that I could form relationships with people, which I had always had a hard time doing.

The relationships that I have made with people allowed me to learn that there are people out there in the world who will care for you. In college, I had different experiences with my emotions. Those emotions consisted of someone wanting to be with me and /or me just wanting someone to be a part of my life as a friend.

In college, I experienced relationships with guys that I had never experienced before. One was the simple thing of someone just wanting to associate with me constantly. I had never had anyone show such an interest in me as a person. That person, Mark, loved to be around me. He loved having talks and called me often. He also had the same condition as I did. What made us

different is that he lived his life like there was nothing wrong, even though, mentally, he was very smart and educated about his condition. He didn't want to take the medication but always expressed happiness easily. All of that went on during the time that I knew him, until it all caught up with him. He ended up dying from his seizure disorder. That really hurt me because it felt as if he was being punished for not admitting to himself that he had a disorder.

Throughout my time in college, I also made friends through the clubs I joined. That allowed me to find a way to open up differently with others. The club activities were put together in ways to allow us to express ourselves. In the Republican Club, I met people that I became close to, knowing and doing outside activities with them.

Outside of school, there were times when we would get together just to have fun. I would sometimes be invited to go out for activities like church, picnics, and even to have study dates. Rarely did I have people in my life that remembered me as I would remember other people who were special to me, like my college friends remembering my birthday by giving me cards and chocolate cake one year.

One experience that I rarely expected, but have constantly thought about, was that of having someone in my life. For me, that experience was very hard, emotionally. Even when given the chance, I couldn't express myself as completely as most girls had by that time in their lives. Personally, it made me feel as if I would always be a step behind. That is a step that I may never catch up to. Even if I did get close to it, it would never be or feel complete.

I personally didn't know what it would feel like to have someone want to be with me. Even if I couldn't put in my 50% of the relationship, they were willing to keep trying. For me, it was difficult to express myself in a close emotional relationship when I have always felt one way because of how people saw me as a person. I could only dream about it.

I had my chance at the relationship in college with someone I will name Tony. It was very difficult. I personally had a hard time accepting the words "I love you" from someone's mouth who didn't look like me. Expressing myself emotionally, even sexually, is difficult. It's like being a baby in an adult suit. I am a person who never learned how to open up to other people.

Special times occurred outside of school as well. One was the chance to perform in the Christmas program to play a classical song. I was asked by Myrna Summers, a professional singer herself, who attended my church (the Refreshing Spring Church of God in Christ). Unexpectedly, she asked me to perform the song early in the year. I accepted the chance to perform. I practiced the song all year up until the Christmas program, which was held at my church.

Going to college felt really comfortable because my father worked there. I went to school there on the work program for their workers. The only requirement that the school had was that the student passes the classes. Personally, I did not mind trying to pass my classes. I was already a hard worker. Tuition was due for the class if the student did not complete or pass the course.

While going there, I did come into a little setback during my second quarter. I had a series of bad epileptic seizures, which

lasted the entire week of Easter vacation. It turned out to be the worst Easter I had ever had. While at church, I was walking in front of the pews during the offertory and, all of a sudden, I had an attack.

Every day for the whole Easter week, I had an attack.

When I went back to school, I went into the computer room to try to work on the computer. All of a sudden, a feeling of blankness or emptiness came over me. Physically, I knew that I had been taking computer classes because I had the proof, the computer books.

Mentally, I could not recall the correct information to help me to perform the work. Recalling information from January to April was very difficult. The loss of information upset me. I began to cry. My life after that seemed to become a big mess. I started having to live my life out of notebooks, pens, and pencils because I just could not trust my brain as everyone else could. If I did not have it in a second location, more likely than not, I was not going to remember it.

Every week, seven days apart, for a whole year when I was in school, I had seizures, regardless of the fact that I was still on my medication. While in school, I had to do a lot of re-reading of material because, every time I got sick, I would forget the information. So, I read the information before the teacher taught it, then again after an attack, and then once more before my exam. To keep me happy, I also kept journals, or diaries, of my life to help my memory as well. It has always been depressing to me that I could not remember what had happened to me. To help me feel good about myself, I began to write down the many good times so that I could remember how good my life has been.

During my time in college, I joined two clubs just to meet people. Guess what? It worked. It helped to open me up some. While I was in school, it made me feel good about myself.

The first club that I joined was the Starship Toronto Club during my first semester. I did secretarial work for that one. The next club that I was a part of was the Republican Club, which dealt with Republican activities. We also had a fashion show to raise money for the club. I did secretarial work for that group as well. I received a Certificate of Service Award from the college for the service I gave to those clubs.

In December of 1996, all of that had to come to an end. It was time to graduate. I graduated with an Associate of Arts Degree in Microcomputers. In a way, I was both happy and sad. I was happy because I had achieved my goal, but sad because the fun that I had at school had come to an end. I really enjoyed myself with the atmosphere of the people and the surroundings. I had not felt emotionally stressed as I had in high school. Now, it was time for me to push for my working and personal goals.

FAMILIES

Families do not realize that, when they do not support their child in whatever they do, they could be hurting that child. People do not realize how sensitive the word "yes" can be. When you say it out of the air, you do not know whether someone believes you or not. You do not know whether that person knows to believe you. You, as a family member, have to learn to be careful about what you say that you are going to do. You could build up someone's self-esteem one day, and dropping it the next.

Families also have to support the child by giving the child the information he or she needs in order to survive in the real world. The protection or decision-making made by parents because of their own personal experiences may not help the child grow up, or it may cause the child to emotionally grow up at a much slower rate.

Families need to take the time to learn about the disorder and spend time talking to their child more. Families also have to learn to accept some of the decisions the child may make as an adult about his or her own disorder. Once the child begins to grow up, family members should begin to acknowledge that. Once the child becomes an adult, they should no longer be treated as a child.

My personal family has put me through emotional stress. That was just as bad as having the seizure disorder itself. It is like having two disorders at one time. That is not right. Nobody has the right to put emotional stress in anyone's life.

FRIENDS

Friends can be a good support system to the child—even if the person is a young adult—and to the family. Friends can help keep the family in line and stop it from falling apart. Families tend to fall apart when they have to deal with a big responsibility. That is where the support of a friend comes in. The friend can help the family get the information it needs and just help in giving extra love whenever the family needs it.

Family friends may know other people who know about the disorder. Those people can also become friends of the family as well.

Friends can be more impartial because they are outside of the direct family unit; therefore, they can help keep up the spirits of the family.

For that to work, families have to stop being shy about admitting to having a child with a disorder and be willing to allow others into their world. Parents have to allow doctors, teachers, and other family members into that world. You might as well allow friends into that world as well. They usually are not going to do harm to the child. To me, they can be a lot nicer than most family members can, because most family members have already made their decision about you. Your friends have to first understand you before they make their decision about you. That is supposed to happen in the family but, usually, the child with the disorder is too young to speak up. The damage has been done before we can learn to speak for ourselves.

CHILDREN

The child with the disorder should build up their self-esteem to become a strong, organized, and independent adult. Below, I will share some of the things that I personally do for myself. They may be beneficial for others as well.

I want you to find your own ways to focus, and to get goals accomplished in your life. You are not going to have your parents or your families to back you up all of the time. Many times, your families are not going to have the time to back you up, so you have to learn how to depend on yourself. After you get into the habit of doing that, it feels so good that you will love to do things for yourself. Do not think that it's because you are becoming a selfish person. You're simply becoming a more independent person.

One thing I do is to make lists for myself. The lists help me when my mind doesn't. Making lists helps me to remember and keeps me in line. I also try my best to keep order in my room. That does not mean that my room does not get messy. What it means is that one type of thing stays or goes in one area. I have a whole bunch of folders that are named and separated by subject. I pay my own bills. Bills that have not been paid go in one drawer. Paid bills go in another drawer. I also keep a goal list on my wall to keep me focused on the goals for my life. Every now and then, I read those goals that are over the top of my bed to keep my spirits high.

All of this can build up over time, so I have to plan time to clean out those areas. About every three to six months or so, I clean out certain drawers to keep order in my life.

Whatever you decide to do while you are a child growing into a young adult, do not let your family control all of your decisions. Sometimes, you are going to have to start standing up to them and tell them how you feel. Usually, you should not holler at family. Personally, I do not believe in hollering. But, sometimes, families can only comprehend one thing—hollering. I am not saying that makes it right. However, learn to stand up for what you believe in—whatever it is.

The most important thing is not to let your disorder control who you are. You are to do your best to try to live as much of a normal life as possible. You need to realize that you are a person first, before you are a sick person with a disorder. When you speak about yourself, do not talk about your disorder unless it is with someone who you know is going to be in your life personally for a long time. When getting a job, save it for after they have given you the job so that it will not be an excuse for them not to hire you.

Present yourself as a normal person but accept that there are still going to be things that you are not going to be able to do like other people. Keep on trying to reach your personal goals. Do not let anyone stop you from trying to do that. Do what makes you feel good and happy. Your family has had its chance to pull their lives together. Now, it's your turn to pull your own life together. To do that means seeing what it is that you can do. Sometimes, you have to go out and test the waters in the real world. Just take a chance. A lot of times, you may have to stop asking for other people's permission to do things, or you may never get the chance to do what it is that you want to do. There comes a time when you have to start living what is usually

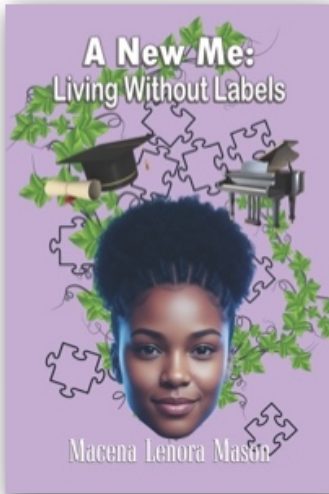
considered a dangerous life by your family. For you, it is maturing.

Keep in mind that there are people in the world who may be ten times worse than you. You could have had another condition that would have made your life like living in darkness. I don't personally know how people who have mental and physical conditions feel on the inside, but I do have a slight idea of it because of knowing someone in my family. He is my cousin, whom I will call Jonathan, and he has Cerebral Palsy, which is both a mental and physical disorder. That disorder puts a lot of pain and emotional stress on the parents of the child because the child cannot move for him or herself.

Keep in mind that you have a seizure disorder, which means that, 50% of the time, you live like a normal person. Sometimes, it's your family who takes the other 50% away from you. Be happy that you do not have to be a totally dependent person like my cousin. Go out there and get your 50%, and more if possible. I personally believe in taking all that I can get. Try to get as close to 100% as you can. You may or may not make it to 100%, but you will do better than those who do not make an effort at all.

What Are Epileptic Seizures to Me?

Epileptic seizures can start on either side of the brain. On the right side or the working side of the brain, a person can have petit-mal (small) or grand-mal (big) seizures. These seizures cause the working side of the brain to turn off. They can also cause the nerves in the body to shake slowly or quickly for short or long periods of time. When I come out of it, I can close my



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