



Hi, I'm Marissa. I am 16 years old, and I have Chronic Fatigue Immune Dysfunction Syndrome.

When I was seven, I became ill. Before I was diagnosed, I had a high fever for over a month and during that time I went to several doctors and had lots of tests done. The doctors said they couldn't find anything wrong with me. Finally they sent me to an infectious disease doctor and he diagnosed me with Chronic Fatigue Immune Dysfunction Syndrome (CFIDS) and Fibromyalgia. Although I have some doctors that do not believe in it, I have others that are firm believers in it and try to help me.

Having CFIDS has changed my life in so many ways. It has been very hard for me to hang out with friends, to be a "normal" teenager or even just to go to school. I used to feel left out. I just wanted to be like the other kids. I have to pick and choose what activities I will participate in. Good friends mean the world to me since it really takes some special people to take the time and understand when I am having bad days, spend time with me when I am hospitalized or

take the time to learn about my illness so they can better understand that I probably can't do everything that they can.

Attending school when you have CFIDS can be a juggling act. Between the illness, the different levels of activity that I can handle, and doctor's appointments, it can be overwhelming at times. When I was in grammar school, I tried to go to school for a full day and I would often end up absent. Now, I go for 2 classes a day and that seems to work much better for me. I go home and rest and then my home instructor comes to tutor me in my other classes. She is the most understanding person in the world. She takes the time to understand my bad days whether it is because I am too tired, in too much pain, or having cognitive issues...better known as "brain fog". She has been simply amazing. When I don't understand something, she finds another way to teach me. She has taught me all kinds of memory tricks. She often talks about "teaching outside the box" and it works for me! She has truly made a difference in my life and helps me to believe that I will achieve my goals one way or another. I hope to attend college to become a bilingual speech pathologist or a special education teacher.

When I was younger, I was picked on because I was sick and I would miss school, go in late or have to leave early. Most of the teachers I've had as well as people on the child study team didn't really get it. They often commented on how good I looked. They didn't realize that I could put on a great act for short periods of time and then would go home and "crash". Many of the kids I went to school with didn't understand the amount of pain I was in or that if I did too much, I would be sick the next day. A simple thing like someone bumping into me in the hallway could really hurt. For a few months, I had my leg lock up and was told to go down the stairs on my rear end. Then they put me on home instruction because I had to use a wheelchair and the school was not accessible. They had me come in after school to meet with a teacher for home instruction. It was a nightmare except that the teachers were really great. Few people really understood when I was in grammar school. The first person that actually "got it" was the superintendent. He was and still is very special to me. He would even let me nap in his office when I couldn't make it through the day knowing that I really wanted to be there. He always found a way for me to take part in things. He always did just a little bit extra for me. He never stopped believing in me and is always there for me.

Although I have been sick, I have been an "A" and "B" student. Now that I am in high school, people don't notice as often that I am not there for some of my classes even if they saw me earlier in the day or that I am often absent. There are still many people that don't understand the illness. I don't get picked on as much because I am not with all the same kids in each class like when I was in grammar school but have even had one person say they wouldn't work with me because they were afraid to catch something. My hope is that I will be able to help educate more people and other kids won't have to go through many of the things I have.

High school has been much better than grammar school was. Some of it has been because the kids are more mature and not quite as mean. Another part is due to understanding teachers that have followed my IEP and done their best to work around my illness. The school nurse, 2 of my teachers and my home instructor are really great with helping me out in school. I am able to go to school more often now because of the partial day schedule. There are still a lot of teachers and nurses that could learn from those who have helped me. Simple things can make a world of difference to someone with CFIDS.

Having this illness has made me appreciate my "true friends" even more. I have 2 friends that are also chronically ill. One has CFIDS like me and he is very special to me because he helped me to understand a lot of the things that were happening to me. He is like a big brother to me.

He lives in VA and I don't see him very often but he is always there for me and so is his mom. Another good friend is also chronically ill but has other things wrong with her. She comes to see me when she can. She knows what its like to have the other kids thing you're different and missing a lot of school. I have a few more close friends that try to understand but it is hard when you don't live with it. Another of my best friends is always there to chat with on the phone or on the computer when I can't leave the house or am in the hospital. Her goal at times is just to get me to smile or laugh and she does a great job of it. Another great friend took the time to read everything he could about the illness, spends time at my house when I'm not up to going out, and even sits in the hospital with me when necessary.

Since beginning high school I have made some really good friends that seem to be more understanding. Some do their best to understand while others simply go on with their lives. That's just reality. The ones that stick around through the ups and downs are truly special people in my eyes. Over the last several years, I have learned which friends are always there and always supportive and they mean the world to me.

I enjoy dance and shopping. I have the most understanding dance teacher/ adopted big brother ever. I dance whenever I can but there are sometimes that I push my self to dance and then later I pay for it. I tell myself that this is one thing that is worth it. He has learned to see the signs of my crashes and tries to help prevent them. He has truly become the older brother I never had.

There are some very special people in my life...family members like my mom who is always trying to help me no matter what, close friends, and some of my teachers. Each one of these people holds a special place in my heart. They have all helped me in different ways and I hope they know that it means a lot to me. They have all helped to make having this illness just a little easier.

Learning to live with this illness is very hard. You have to choose which things you will do because the next day you might not be able to do anything at all because you picked something that used too much of your energy. Some days I can act like the other kids and other days I can't even get out of bed

A lot of people think that it is crazy that I know so much about my illnesses, but since it is my body I feel I should know what is going on with it. I am glad that I know so much about my illnesses. It helps me in many ways, such as knowing when I am in for a "crash". Though sometimes I try to avoid giving in to the illness, it can get you when you least expect it if you don't listen to your body. It leaves you feeling helpless at times.

For me, the trick is to make a difference and try to work to help in finding a cure. Over the last five years, I have run a gift auction that has raised more than \$20,000 for the NJCFSA Research Fund and Medical School Scholarship Fund. This year, I was very excited to see \$10,000 be allocated to a special research project.

I guess if I had to give someone advice about having this illness, I would say stay positive. Make a difference any way you can. Hold on to the people that are there for you and supportive...and reach out to others that go through the same things you do. Appreciate all the very special people in your life and believe that one day a cure will be found with the help of organizations like the NJCFSA.