

## **The Letter I Would Like To Have Received From a Friend or Relative During My Illness**

**By Alex Florkowski**

My most darling daughter,

How I wish that I could hold your hand every waking second of every day forever and ever. My sweet nine year old, how life's cruelty has hit you so hard, so young in life. Your frail, fragile body undergoing so many different things at once. The surgery for the insertion of the infusion port and then the second surgery for the removal of the cancerous Pituitary Tumor. Chemo therapy and then radiation on top of it all. I only wish that we had found out about your brain tumor quicker. I write this letter to you now explaining the events which we could not explain at the time. I want to share with you what was going on and express how we all felt about it. You were too little at the time to understand what was going on but I don't want to leave you in the dark about what was going on when you were sick.

You were perfect from the moment I held you at birth until this very second in the unfamiliar, cold, unfriendly hospital bed. You were sweet, stubborn, beautiful, strong-willed, and kind all at the same time just as you still are today but something was terribly wrong. I know that having divorced parents since the age of two and two stepparents since three years old is tough, but there was more going on than the normal divorced family issues. We knew something wasn't right, and from six until eight years old, you were misdiagnosed and misunderstood.

You were always having trouble in school. Your first grade teacher would call

home numerous times a week concerned about you. You were never able to focus and were always distracted and we never knew why. But it wasn't just the attention difficulties in school and at home, there were more complicated and frustrating problems that none of us understood, including you. The constant drinking and going to the bathroom every five minutes (and I'm not exaggerating.) We assumed it was for attention or for getting away from class. Little did we know how wrong we all were.

The drinking and going to the bathroom wasn't all of it though. You were not eating all together no matter what we tried to feed you. We tried all your favorite foods, we even tried just cookies but you pushed it away always sickened by the thought of eating anything. Your father would sit you on his lap trying to force feed you for fear you would starve. You had lost weight to the point where it was dangerously unhealthy and you were deteriorating with each day that passed. All you ever wanted to do was drink, drink, drink. I'll never forget when your second grade teacher got so tired of you asking to go to the bathroom that she just stopped letting you go all together. One time you had to go so badly but she said you'd have to wait and you ended up wetting your pants.

We tried everything to try to get you to stop drinking and going to the bathroom so much. We even tried buying you a toy if you wouldn't go to the bathroom or drink for a half an hour. Most of the time you were secretly going to the bathroom upstairs and drinking from the sink. You could never wake up to go to the bathroom at night. You would wet the bed every night most of the time more than once. You father would set his alarm for every hour just to wake you up to go to the bathroom.

Then of course there were the behavioral issues. The uncontrollable tantrums and

suicidal thoughts at seven years old. Of course you had no control over all of this, but no one knew that at the time. We took you in for medical tests and you were misdiagnosed as a defiant child by your pediatrician. And we believed it true. The doctors never did the right tests for the right thing and consequently, you suffered for two years. Life went on terribly slowly for all of us. We were frustrated and worried and had no idea how to help you. You refused to eat and we thought we would have to have a feeding tube put in you because we didn't know what else to do.

You would throw up constantly whenever you were nervous. When I, your brother, your stepfather, and you took a trip to California along the coast, we had to pull over to let you throw up more times than I can count. You had to pull over to go to the bathroom because you couldn't even make it to the next rest stop. You had huge black circles under your eyes. You were pale as a ghost, and your hair was horribly unhealthy.

You started developing obsessive compulsive behaviors such as constant blinking of your eyes. You had hallucinations like when you went to Florida with your dad and brother, and you swore on your life that you had swallowed a quarter. Your dad knew that it was impossible for little you to swallow a quarter but you swore that you did and you really believed it. It was the tumor messing with your head and no one understood. You were alone in this world with no one who understood you.

We couldn't get you to go to school. You would wake up in the morning and sit on the couch ferociously biting your nails anxious to have to go to school. You would almost get physically sick on the way to school and someone would have to hold you in

the parking lot before they had to drop you off. You never wanted to go and we a lot of the time allowed you to stay home. If you didn't stay home, then you were in the nurse's office for half of the school day.

We took you to numerous therapists thinking that all these symptoms of a brain tumor were behavioral. You didn't understand how you were thinking and didn't know how to express it so we would sit with you trying to get you to tell us what was wrong. The therapy, the yelling at you because we thought you could control all of this, the countless number of tests that were run all for the wrong things were all for nothing. The attempts to stop your drinking where all useless because your body thrived on it to survive. You would sneak drinks when we tried to deny you them because you knew your body needed it.

Finally, after being told over and over again that there was nothing wrong with you except that you were a defiant child, your step mother used her nursing background to have specific tests run. You started showing signs of diabetes and she went to the pediatrician and had thyroid tests and diabetes mellitus tests done. They came back all screwed up and we were sent over to get a Cat Scan. We found out the worst imaginable news any parent could ever receive.

You didn't have the normal diabetes, you had something called diabetes insipidus which was the cause for the constant drinking. You also had a germinoma cancerous brain tumor. I'm pretty sure we were all in tears when we found out. The doctors did a spinal tap and found that the cancer had aggressively spread to your spinal fluid which is basically a death sentence. Our nine year old daughter was going to die. What was so

precious to all four of your parents was going to be wrenched from our hands and taken from all of us forever.

Just when we had all lost hope and were facing the fact that we were going to lose you, a miracle happened. The doctors redid the spinal tap and found that the cancer cells that had been in the spine were miraculously gone! God had touched you with his hand and chose to have you live because he knew you were special.

So my daughter, there you sit in your hospital bed, bald as a new born baby. I know that this is all so overwhelmingly scary and miserable for you. But I always want you to remember, you are a handpicked angel of god. You are my hero, now and forever. I don't know any adult that has gone through what you have as bravely as you are. You are my love, my darling and I will hold onto your hand for as long as you need me to.

I am so sorry that you were misunderstood and called a defiant child. I am sorry because no one, especially a child should have to suffer through what you are. You are a special little girl and even though you will miss half of your third grade year, I know that you are intelligent enough to make it to the fourth grade next year. Just remember that you are beautiful always, even now, if not more so with your little bald head. You keep me strong and we will get through this together. I love you with all my heart.

All my love,  
mom

PS: I feel that it was important for me to express this letter in this way because it was

very confusing for me to understand what was going on at nine years old. I was so young and too immature to comprehend all of this. My parents weren't going to tell me this because number one, they all thought that I was going to die, and number two, when you have a sick child, the last thing you're going to do is explain how much they've suffered for two years. Having this experience so young in life has caused me emotional issues at different times in my life. My childhood was stolen from me for a long time. Even though I was fully cured, it took me a long time to readjust into normal life. I wish that during my time in the hospital, someone had tried to tell me all of this even though I probably wouldn't have understood it. I appreciate every second I breathe. I don't wallow in self pity or look at it like "Oh poor me, what did I do to deserve this?" I look at it as that it has made me a better person who is said to be mature beyond my years. Now I am a more compassionate and caring person than I might have been if I didn't suffer from cancer. I am alive and loving it and almost nothing gets me down. I feel so blessed that God gave me a second chance and I will never forget it. Now at sixteen years of age, I still remember what I went through before and after the day I had my first cat scan. And I'm glad I remember because without that memory, I might be like so many others who don't appreciate how lucky they really are. I feel so blessed that I am just here and able to write this essay, when I know that so many are not as fortunate.