

When my brother George was born, I had just turned four and was ready to accept all the responsibilities that go along with being a big sister. I was ready to protect my brother from bullies, teach him how to build Lego castles, and show him how to play piano. As he got older and was diagnosed with Tay-Sachs, I realized that things were not going to work out as I planned. There would have to be different ways to be a good big sister.

I have so many memories of my brother. George loved chocolate cake when he could still eat solid food and he would “talk” after every spoonful. After he could no longer eat, I would still give him tiny pieces of Hershey’s kisses and let them melt in his mouth. On good days, when I said his name, George would smile and his eyes would light up. I was very protective of George and I always wanted to make sure he was comfortable. I would gently stretch his legs out for him when I noticed he was curled up for a while on the couch. Sometimes, when George needed to eat, I would be the one to carefully hold up his feeding tube (not too far high up, because then he would get a stomach ache) as we watched Sesame Street together. When his heart rate suddenly increased, I would play his favorite song “Somewhere Over The Rainbow” on my harp for him in order to help keep him calm. I used the suction machine for George when he needed it. Sometimes, I would just hold his hand or rub his hair. I know that he knew that I was there for him.

I did not want to believe that George would die. I had not experienced death before and I could not picture my life without George being in it. I did not want to believe that one day, when I was 10 years old, he would just stop breathing. He passed away when he was six and a half years old. I believed that George would be a part of my life forever. After his death, I found that he still was. I still consider my family to be a family of five- not four- and I still consider myself “the middle child” rather than “the youngest.” I still think of my little brother often.

When I think of George, I am filled with a mixture of sadness and happiness. I think of his adorable smile and gentleness and how he was able to appreciate and enjoy the simplest thing in life. The memories that I have make me smile. Although George brought my family and I much happiness, his life was not easy and it was not easy for our family to watch him struggle. It was difficult to see George lose his skills

and watch as his smiles and giggles became rare occurrences. I had to witness my family struggle to take care of him and deal with life and death decisions. I still think about what he might be like if he had not had Tay-Sachs.

George experienced joy in the wind blowing on his face, in smelling flowers, watching twinkling lights, listening to music and getting hugs and kisses from his family. I try to live in the moment, and I do my best to see the simple joys in life. I learned not to take things for granted and to appreciate friends and family. Even in his short life, George had a strong impact on so many people. George taught me that even one person can have a very significant influence on others. I saw, first hand, the love my parents had for George and the emotional connection that all of us had with him as we cared for him every day. I know George was not able to grow up to be the person he might have been and so I try to take advantage of the opportunities I am given.

Currently, I am pursuing a double major in music performance for the harp and media studies. Music can be powerful, and I want to create things that make people feel something through music. I want to evoke emotions in others, and I want to inspire people to think about what it means to be human, even for a moment. Like music, life is ephemeral; and I intend to appreciate and try to make the most of it.