



## **Writing Our Journey: Poems and Essays by Family Caregivers**

Each meeting has a suggested prompt, or idea, for people to write about. Everyone is free to interpret that prompt however they'd like. Below is one of the prompts, followed by a sampling of what was written in response.

Please remember that each piece of writing belongs to the writer and, if quoted, must be credited to that writer.

### **A time you made your child happy**

Write about a time when something you did made your child happy, or helped him/her feel better than they had been feeling, or helped the two of you connect with each other in a positive way.

- "Wel come, Mom", by Lisa N.
- "Jammin'", by Dorothy Ryan

## “Welcome, Mom”

Words join us, sustain us, complete us. For my son Eric and me, it's been a slow journey to build such a bond with words. Let me explain.

When I was a child I loved dolls, real baby dolls not fake Barbie dolls. I played with baby dolls long after my friends had stopped. In fact, there was only one thing I loved more than a baby doll, and that was a real baby. So, I babysat as much as possible, always loving my time with babies. I could comfort really fussy babies and always felt pure joy being with them. I couldn't wait to grow up, get married and have four boys whom I would love and cuddle. My boys would love me and know me as their Mom. To be a Mom, that was my dream.

Many years later I was elated when I gave birth to Eric, my first baby. I can still hear the Doctor pronouncing that I had given birth to a beautiful baby boy. He was the best Christmas present I had ever received. I couldn't wait to snuggle MY baby boy. I was ready for the rest of my dream to unfold.

The following days unfolded, but not as I had envisioned. My baby was in the NICU; he was very sick. He was miserable, rarely taking a break from crying. The bleak situation was compounded by the fact that I was not allowed to pick him up, I was not permitted to cuddle my baby! The first weeks with Eric were reduced to hovering over him in an incubator and stroking him with a single finger.

The feeling that my dream was turning into a nightmare was confirmed when I looked up one day to see a sign above my baby which read “irritable”. He was near impossible to comfort, but at the time I didn't know that babies with developmental disabilities, specifically cerebral palsy, are often labeled “irritable” as they are difficult to comfort. All I knew was I felt awful for my tiny baby. While Eric cried, I was beginning to wonder if I was already a failure as a Mother. Why couldn't I comfort him? What was wrong with me? Why was I being rejected by my baby?

Weeks later when my baby finally came home, my childhood vision of motherhood seemed even more elusive. There was no snuggling and very few quiet, bonding moments. Not with my baby. The truth was that my son was irritable, really irritable. He insisted on being walked while being held in the “football” hold. When not moving and facing the ground, he cried. And cried. And cried. He was a poor sleeper, seemingly never sleeping soundly unless it was time for his every-three-hour forced feedings and blood sugar checks.

Exhausted and heart broken, every three hours my husband or I would return to our new routine: warm the milk, put on upbeat music, began the hour plus effort to get Eric to drink a few cc's of milk, listen to our baby scream as we checked his blood sugar and then back to "walking the boards" with our now wide awake and most unhappy baby. So it went, in three hour increments day after day. It felt like each time we finally got Eric calm or asleep it was time to start with the force feedings again...

I had so many hours to contemplate my inability to comfort my son. The son I had dreamed of all my life. I had gotten exactly what I had dreamed for, except I didn't. My baby was different. My baby was sick. My baby was hard. My baby seemed to reject my efforts to comfort him. I was disappointed, I was profoundly sad. How could it be that after all the years of practice, I couldn't make my own son happy? What was I doing wrong?

My perceived rejection by my son went to my heart, to my soul. After months of being home with Eric I couldn't take it any more. Instead of taking a one year maternity leave as planned, I returned to my career after only six (long) months. I couldn't stay home, I was a failure there. I was depressed. I needed to get out. I needed to feel successful again at something, anything.

It was decided my husband, Bill, would take a paternity leave and care for Eric. Bill was up for the challenge and didn't take Eric's behavior personally. Bill never felt rejected by Eric. Soon my husband decided to quit his job, and while maintaining his role as primary parent, he returned to school to become a Physical Therapist. Upon graduation he obtained a part-time job in a school working with children with special needs.

So, while my husband "held down the fort" and began a career in the special needs world, I dug deeper in a different direction, into a demanding corporate career. I was having great success at work and my pay check reflected that, but, it came at a price. I often came home tired and impatient and that combined with my very demanding and hard to comfort son, didn't bring out the best of either one of us.

I was rarely the preferred parent, and that stung. Intellectually I understood why Eric was more comfortable with my husband, because they spent a great deal of time together. However, the pain of his preference went through my heart to my soul. I continued to feel rejection from the baby boy I had dreamed of all my life.

As the years passed Eric and I forged a strong bond. It was not always pretty, but our love for each other was understood. Thankfully, all those feelings of rejection have begun to fade. Things started to really change when I retired from my draining job and I began my journey of healing. With renewed energy I found more patience for many things, most importantly my son. I no longer take his moods so personally and our relationship has grown more positive. I take more care to avoid his "triggers" and I no longer abruptly leave conversations when he turns them negative. Instead of being hurt and rejected by things he says, I sit quietly with him. I try to be present and to accept the moment as it is without bringing in the pain, the rejection, of the past.

I have also started making a point to say 'thank you' to Eric at every opportunity - when we have a good conversation or a good time together. My "thank you" is always heartfelt. I am profoundly thankful when we are sharing a bond I know he has with only me, his Mother. These moments are made perfect when I am rewarded by my son saying "Wel come, Mom". Although perhaps unintelligible to an outsider, these words ring clear through to my heart. For they represent the fruition of my dream, which began in childhood, of that special bond a mother feels with her child.

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## Jammin'

Tuned in to rap songs  
drivin' to work,  
my daughter and I  
are jammin' without instruments,  
improvising lyrics  
with Snoop Dogg, Lil' Wayne,  
Missy Elliot. Next up  
is Kanye and we burst out laughing,  
feeling like we, too,  
"Touch the Sky."

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