



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 moment when you really understood your child had a disability

Write about that moment (or moments) when you really understood that you had a child with a disability. For some of us, that might be the moment of hearing a diagnosis (whether at birth or long after). For others, that might be the process of nagging doubts that gradually form an undeniable truth. Such understanding might come from overhearing a careless comment made by an acquaintance, or something small but significant your child said or did. The idea here is to write about what that time was like for you, and the feelings it engendered.

- "Appointments", by Brenda Considine
- "STOP", by Gail Frizzell
- "Walking", by Lisa N.

Appointments

I arrive on time at your badly lit office
where I wait with my son,
Who thrashes at your coffee table
piled with 'Popular Science' and Jr. Highlights.
He blows the dust off your faded silk flower arrangement,
Enchanted by the paisley swirls it makes in the air.
He ignores your colorful plastic toys,
preferring instead to trace the patterns in your stained berber carpet.

I am always asked the same questions.
About my pregnancy.
About my delivery.
About nursing.
I check the boxes. I fill out the form. I am compliant.

Yes. This was a 'wanted' pregnancy.
No. I do not smoke.
No. I did not drink alcohol.

My answers are always the same, every time you ask.

Like a witness, I tell the truth, the whole truth.
Now, you must do the same.

© Brenda Considine

STOP

It was just a regular stop sign, a red octagon with bold white letters – STOP. I'd probably seen thousands just like it in the past twenty-nine years. But this one was memorable. In fact, it's my clearest memory of that day. It was so much more than a traffic command. It represented the end of more than a road. It represented the end of the life I thought I was leading. It represented the end of the life of the daughter to whom, I thought, I had given birth. The road beyond that point would be unfamiliar, twisting, and scary. A road I didn't want to travel. So, I sat at the stop sign.

The stop sign was at the end of the hospital driveway. The hospital where we had just heard the news that something was not right with our beautiful, smiling baby. How could anyone think that my pink and white, sleeps through the night baby was anything less than perfect? I had stenciled forty-four peach colored bears around the walls of her room. Each held a yellow flower. Peach and white gingham decorated her crib. I had read every book. I had drunk my milk. I had done everything right. What did I miss?

They said developmental delays, "See a pediatric neurologist." I had never heard of a pediatric neurologist. He said, "Let's do some tests." There was no diagnosis, but he said, "I believe your daughter will not develop cognitively beyond the age of seven. Let's do more tests." A year later came the diagnosis – Leber's Congenital Amaurosis. Can you repeat that?

I did the research. That's not my baby. My baby can see. My baby has healthy kidneys. What do you mean, she's 'atypical'? Please be wrong. They weren't.

In hindsight I know that even though I was hearing things I did not want to hear, I had been the first one to know that there was something wrong. I had read every book. I knew that her development was not progressing correctly. I just wanted someone to tell me that I was wrong. Me, the type A, perfectionist, know-it-all wanted more than anything else in the world to be wrong. I just wanted everyone to be wrong. We weren't.

Because I had picked up on a problem and started asking questions before anyone else, Lauren was in therapy and receiving care very early. Yet, I treasure those first four untainted months. Months when I was blissfully ignorant of the way her life would unfold. Months when I simply enjoyed this new life that was enriching my own. Months of joy, before a stop sign would represent the end of our lives as I had planned, dreamed, and expected them to be.

© Gail Frizzell

Walking

When do babies start walking?
Normally by 18 months.
When will my baby start walking?
Perhaps in the next few years.

There's plenty of time.
There's plenty of hope.

When do we adjust the goals?
Not for many years.
One Two Three Four Five Six
Seven years crawl by.

There's no more talk of walking.
We've moved on, without a single step

© Lisa N.