



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.

Ambivalence

Write about the word ambivalence.

- "Certainty" by Lisa N.
- "How Many Times Do I Have to Tell You?" by Kathy Mullery
- "We Are All the Same, Everyone is Different" by Ann C. Martinelli

Certainty

I studied Economics.
Learned about assumptions.
Arranged numbers, contorted data.
Got the right answer.

Then in corporate America,
I handled complaints.
I knew what to do.
Arranged the facts, wove the story.
Defended our firm.

Nothing is so clear now
Data and assumptions are meaningless
Rearranged facts don't change my story.

My questions go unanswered
Yet I often search for clues.
Longing for certainty again

But today I will try
to take it one minute at a time
breathing hope
seeking joy
smiling at the world.

Today I will
embrace all that is good
refuel my soul,
wait.
The
answers
may
come

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How Many Times Do I Have to Tell You?

Maybe parents everywhere, before they've even had their second cup of coffee, are fighting with their 14-year olds about what they can and can't wear to school. That is what I tell myself, but really I am not sure. In the nanosecond that it takes me to transport back to when my other son was 14, I try to recall, to find some explanation to satisfy the constant worry and usual conclusion, that it is my son's disability that makes him so obstinate. I look for something, anything that normalizes that we had this same argument yesterday about this same red shirt, the one you'd wear when running on outdoor tracks or treadmills, but not in middle school hallways, the one that I can just picture the other kids pointing to, silent smirks on their faces, passing my kid, alone as he is, in the hallway. I think back to my sisters, my friends, anyone who might have told me their tale of teenage woe in the mornings, stories of stand-offs in the kitchen. Was it a skirt that was too short, pants that sorely needed a belt so as to at least partially cover those boxers? No other moms in the present to compare notes with, I rely on the past. But right now, when I need those stories the most, I can't think of anything.

I am repeating my arguments of yesterday with my son and I can't tell if this is normal. Why is it important for it to be normal anyway, I wonder, fully knowing this is an unhelpful direction for my rambling thoughts, knowing, too, the arguments I am repeating are not just the ones with my son. What you don't need, I tell myself, is to let yourself get distracted once again by useless comparisons, when you need your full energy and attention to this boy in front of you with his arms stubbornly crossed, asking "why" for the sixth or seventh time. Yes, why indeed.

I walk away and once again, that proves the best approach. He wants to please, after all, so by the time I am out of the shower he has changed into a suitable shirt. He is still wearing the sweatshirt he also loves so much and I find that I approve.

He spends longer than he should, searching for these items, the right fit, the right look. There is no rushing him. Let him ride out the adolescence, let us both ride out the worries we have in the morning. He takes a final look in the mirror and is satisfied, sure he looks cool. He's as sure as he can be at 14. As sure as any of us can be. I too, steal a glance at his reflection, struck suddenly at how much he looks like his brother.

© Kathy Mullery

We Are All The Same, Everyone is Different

“Don’t ask me any questions about school; I just walked in the door!” This was Joe’s mantra from the time he began speaking with complete thoughts, at around ten years of age. The first time I heard it I thought to myself “Joe can’t walk, what the hell is he talking about?” Whenever I asked he would say “You know what I mean!” It was around this time that I began to think and consider what Joey’s perception was of himself and his disability.

He’s never said “I have CP so I can’t do that”. We’ve talked about his disability many times in a variety of settings. There are things that are more difficult with a power wheelchair. We always have to consider accessibility and discuss it when planning for trips, even short ones to an unknown restaurant or a new friend’s house. As a family, we too have never said “oh we can’t do that because Joe can’t”. We always figure something out that will work for each circumstance. I have also had discussions with him about what CP means and that he was born prematurely with significant complications. He understands why he has to take medication, too. He remembers his last seizure. Joe was involved in the decision making process to have a baclofen pump implanted in 2004. He gets it, I know he does.

Did our family dynamics influence him? Yes I’m sure it has. And my husband and I also made a conscious decision to include Joe in Challenger sports so he could, as I put it “identify with his disabled peers”. (I’m sure I heard that from a well meaning professional!) A funny thing happened, though...Joe always gravitated towards the “buddies” in Challenger sports. In school, he would only speak to or spend time with his peers who did not have visible needs. I can look back and pick out who influenced Joe: the social worker who talked to him about the Yankees and asked Joe and his Dad to play golf with him. They figured how to use Velcro straps to safely seat Joe in a golf cart; the classroom assistants who asked Joe for his email address treated him no differently than any other person they met; my Dad, who didn’t let a wheelchair keep him from wanting to share his love of fishing with Joe. It took a few months, but my Dad researched techniques he could use to secure Joe’s manual chair to the cabin of his boat. Joe knows, too, which relatives are comfortable with him and who isn’t – he steers clear of those who aren’t.

Joe’s uncanny perception has led our family to self-direction, and how we choose people to support Joe. We believe that people who will support Joe best are those who have never directly worked with someone with a developmental disability – we don’t want stereotypes to be part of the relationship. They meet Joe and see him as a fellow citizen, a peer who may do things differently, but don’t we all? Joe has taught me that we are all the same and that everyone is different.

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