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 Transition of Your Own

The prompt is to write about a transition in your life. We talk so much about our children’s transitions, but what about our own? What about those times of big change? Pick one of those times, and think about the different feelings it engendered. What were you moving from? Moving towards? What did you learn? How did you change in the process? Is there someone who helped you navigate the particular challenges that arose?

- “Unmoored” by Gail Frizzell
- “I Wish You Understood” by Lisa N.
Unmoored

Your leaving
has weighed the anchor
binding me
to the minutes and hours
to the need and the want
Directionless
I wander
heading unknown
Your life
has been
my compass
and now
unmoored
I drift

© Gail Frizzell
I Wish You Understood

I'm not complaining, or maybe I am. I just want you to really understand.

I don't get to choose. From the moment I am woken up, until the time I go to bed, my day is completely structured around my son. His basic needs (repositioning, eating, drinking, toileting), his feelings and his schedule take precedence. What I want, what I need, is ignored.

When I help him drink, I don't know if the liquid will end up swallowed, drooled on his clean shirt, sprayed on my clean clothes, in my eyes and/or in my mouth. I am overweight, yet constantly around his food. I am faced with slow, frequent feedings. While the food chosen by him and prepared for him is often refused, I nibble unconsciously. If my guard goes down, unanticipated coughs spray me with saliva, food, snot. In my hair, on my face, on my neck, in my ear.

Conversation is not easy. Like speaking with a person who knows little English, complete concentration is required. Light-hearted banter is nonexistent, yet I try. He utters a single word and then I am expected to build the sentence, complete the thought. I am given clues, but my questions for clarification often go unanswered, or I’m told “I don’t know.” All the while, innocent, random, spastic moves pinch, grab, scrape. Involuntary, unintended to cause harm, yet painful nonetheless.

Out of the blue, for no reason I can pin point, it starts. His grinding teeth, Groaning. Moaning. I tense up, my pulse becomes rapid. More noise. Crying. Screaming. “Click click” of his carelessly driven power wheelchair. Crashing is heard as the wheelchair bangs into walls, doorways, furniture. I wonder, “Where is this going? How long will this last?”

My son is hyper-sensitive. He acts however he feels. Yet, my mood is expected to be good at all times. Any negative energy I reveal is absorbed like a sponge, so I must be on guard, watch what I say, be careful how I act. I must be positive even when I’m not, or my son will act out.

The path of least resistance leads to bad habits, but I often don’t have the energy to do what’s best, so I indulge: I do it for him. I finish the sentence. I make the decision. He wants to be passive, so he’s delighted. But, I have failed him.

The ever-present reality is the limited, preplanned “freedom” in my life. My time, my desires, take the back seat to my son’s needs, his moods, his schedule. Since my son thrives on routine, any change in his schedule or his routine
causes hours of repetitive questioning: When? Why? When? Why? How long? Why? When… Words which used to describe me, “fun, flexible, spontaneous,” have been replaced by “tired, moody, trapped.”

Even when I am smiling, it’s there. The knowledge that I will likely get interrupted, abruptly brought back to what my life has become.

I just wish you understood
that while every day isn’t bad,
attending to his needs
being repeatedly spat on
trying to communicate and build a relationship
always being on guard, careful not to shift the mood
hiding my true feelings,
fearful I am failing my son
while being pinched and feeling trapped
can become unbearable.

I just wish you understood. It’s so ever-present. So sad. So suffocating. So maddening.

Always on the edge.

© Lisa N.