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.

Resilience

The prompt is to write about the word “resilience.” In the world of psychology, resilience has to do with the ability to cope with stress and adversity. What are the factors, either within you or surrounding you, that help you deal with the difficult challenges of life? What feeds your resiliency? What depletes it? When you say, “So and so is such a strong person,” what do you mean? How do you define “strong”? You can write about this concept as it related to you, your child, or anyone else you know.

- “Wwwwhat Happened” by Kathy Mullery
- “Blisters” by Brenda Considine
- “A Determined Path” by Ann C. Martinelli
- “Containment” by Gail Frizzell
Wwwwhat Happened

“Yyyyyou know what that kid did,” my son stammered to me. I wasn't prepared for this sudden mood change, the angry tone, the complaint that was coming. Three seconds ago wasn’t this day like every other, didn’t I just watch his school cross country meet that ended like every other and watch him hop in the car and take a long swig of water. I sip from my own water, hardly notice my hands a little tighter on the steering wheel, turn the radio down and then steel myself for what is coming.

Chris seldom complains and I worry when he does, that I will come up short. I will take this fragile moment of opportunity and blow it. He won't be any smarter or wiser or less disabled after he confides in me. The world around him will still be confusing, no clearer, no roadmap or formula for fixing any of this. I think, even on some of my best days, I am failing to raise him well, or bestow to him that extra dose of strength I think he will need.

But ready or not, I would hear the rest of this. He would finish the thought. I would accept the challenge, do my best to figure out what he was saying, persist until convinced that I had and understood the full story. I would put myself in his shoes and if there was a way to feel what it must be like to be him in this moment, I would try. I would process whatever he was about to tell me. My heart ever so slightly skipping a beat, I then picture placing his complaint on some point on the continuum between fantasy and that which requires a call to 9-1-1. Calming myself, I next imagine offering him a simple explanation: “That kid doesn’t know you.” “That kid thinks this or that.” Maybe I will suggest a quick solution, even if a trite one: “Don’t worry about what anyone else says and just do what your coach says.” I might dismiss the complaint all together, knowing as I do, that reality and fantasy intersect on some mysterious plane for Chris and maybe, therefore, there was no “kid.” Yes, possibly a dead end and I wonder if what I am now feeling is relief. Or, oh dear, what if I am about to hear something very grave and scary. I am ready. We will do what needs doing.

But I am already exhausted. I am weary thinking all of this before Chris has even finished the sentence, slow as he is to form sentences.

“Hhhhhe said I can’t cut.” “He said you can’t cut? What did he mean? Who said it? Is it because…” and I was off, now operating on instinct.

We got through it. It’s the end of the day now and this seems like a distant memory. I don’t even know why I am thinking back to it. I am daydreaming, I guess, until I hear my son’s voice again, loud and clear and slow, interrupting me. “Mmmom, know what happened?” This time, there's a smile on his face.

© Kathy Mullery
Blisters

At recess, first grade girls line up, waiting their turn at the monkey bars where they will hang.
Rocking, arm over arm, they pull themselves forward across the cold metal rungs to the other side.

There are unwritten rules of play:
ever cut in line;
if you fall midway off, you get to start again;
one way only;
and the blister rule.
If you get a blister, you stop. And rest. And heal.

When she began, my daughter’s hands were soft and fleshy. Still childlike.
But now, her palms have hardened.
Tough layers of skin built up in places of grip and wear, protecting her from repeated overuse.

The calluses look strong and hard but sometimes - for reasons unknown – the thick white rinds of skin peel open; a fleshy flap lifts, exposing an oval of raw, pink tenderness underneath.

Now, life compels me to swing and grab that bar slightly out of my reach;
I am suspended, crawling through air – knees bent, twisting and swinging, hoping I can hold on, that I will not drop off.

Every day, day after day, I move in one direction. I harden; I thicken in places of pressure and wear. I callous.


© Brenda Considine
A Determined Path

Joe’s resilience was evident from birth. He was never supposed to achieve any of the things that are part of him today. He fought a traumatic, premature birth and then pneumonia at three weeks of age. He battled with infantile spasms; oh how he fought those bastards! Up to 200 a day, single seizures, clusters of them for over a year. He battled septicemia when he was seven months old. He clashed with obstacles that no one ever dreamed existed.

And then he smiled.....he was eight months old and lying on the sofa as I tied the hood of his snowsuit to bring him outside to see his sister riding her new bicycle. We were the last to get ready on that cold March day in 1985. I looked at his face and couldn’t believe what I was seeing! One tiny smile. He smiled and I knew he would learn. He coped with the seizures and refused to give up.

Early intervention physical therapy occupational therapy daily injections of the steroid ACTH for six months speech therapy looking at family members as I said their names he knows who they are! sleeping through the night eating real baby food going in the pool eye surgery getting his first wheelchair going on the bus by himself Mrs. Farin notices he’s laughing when she says something sarcastic to another adult! Adductor and heel cord surgery liking baseball just like his sisters going to baseball games playing baseball fishing on Boppy’s boat let’s go to Disney World! let’s go to Disney World again! adductor and heel cord surgery again hmmm I think he likes talking on the telephone doesn’t like school anymore but who does at 15 really doesn’t like school anymore but does like hanging out with the teachers, aides and therapists baclofen pump surgery oh shit he’s got an infection more seizure activity back to the hospital prom king graduation hiring and firing support staff volunteering at Prevention First and Vonage radio show! baclofen pump recalled take it out put a new one in going to the Chelsea playing bingo and pokeno with the old folks boardwalk Asbury Long Branch Avon facebook brookdale Nicole.

Joe’s tenacity of spirit leads him; he is often fearful to try something new, but once he decides to move forward, he is resolute. Joe is changing and leaving some old roles behind because of his resilience. His spirit is pure and honest. He’s continuing to create a life full of love, learning, interdependence and community. I marvel at his abilities. I know he doesn’t see his disability as a barrier; and no one else should, either.

© Ann C. Martinelli
Containment

Lines drawn carefully  
point to point  
like a child’s connect-the-dot picture  
outline barriers  
within which  
the unpredictable  
the uncontrollable  
are contained.

Illusions of normality  
created within walls  
of routine and order  
form perimeters  
for living a life  
bent on anarchy.

Deliberately crafted boundaries  
enclose  
the every days  
within which  
one learns  
to color within the lines.

© Gail Frizzell