



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.

Impact of having a child with a disability on a choice you've made

Think about a choice you've made that has really mattered to your life. How did having a child with a disability influence that choice? Your career, where you live, an interest outside of family and work – these are some examples of the kinds of choices you might want to write about. How did you feel at the time you made that choice? How do you feel about it now? Were there things that came out of that choice (good or bad) that you didn't expect?

- “Complications” by Lisa N.
- “STUMPED” by Dorothy Ryan
- “Learning to Drive” by Kathy Mullery

Complications

Eating?
Sleeping?
What's the mood?

Up for it?
Out of steam?
What to do?

We divide.
Two will go.
Two will stay.

Why so hard?
Disability
Constant
Complications.

Another day.
Without warning,
Our niece is dead.

Far from us
In the west
Her baby cries.

Family calls.
How can we go?
How can we not?

Again, the divide.
Two will go.
Two will stay.

Why so hard?
Disability
Constant
Complications.

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STUMPED

From the time my daughter was a seedling her needs have sprung up and branched out
in all directions, blocking the paths I've chosen for myself, forcing me to cut back,
retreat or forge a new way, sometimes miles from where I intended to be.

a well-planned life
pages scattered in the wind –
going with the flow

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Learning to Drive

“Well, you have to pass a test first and, you know, that will be really hard because you have a disability, you know?” The topic was learning to drive and the run on words were the nearly the same ones that had been roaming in my head for a long time now. When was the best time to tell him? Was there a right way to say it? Would his feelings be hurt? Could he possibly understand? Would the words be spoken, the message sent without any flinching at all. And then there was the thought of his potential answer, the give and take started, this conversation that had so far been only with myself. Would it now just proceed like some unremarkable understanding between us, like we were simply speaking of our shared experience, nothing fragile, something anyone could recognize, ordinary and of little notice like the weather or any other common truth?

Still, I surprised myself that I so suddenly spoke the words. There it was. The decision to tell him, before the conscious registering of it. The Rubicon passed. The roaming, the pre-occupation over. Then his answer: “I know.” That’s all? “I know?” The rehearsals, those nagging conversations in my head had never figured on this answer. What was all the fuss about? We do know, both of us, I thought, don’t we. This business of learning, learning to drive, learning about your disability, learning how to say it, is hard.

We know the test will be hard. We know that, in a couple of years, everyone else your age will be taking this test and passing, and you probably won’t be yet reading at a level to understand all the questions. We know there will be more questions, more decisions about what to tell you, how to answer you, when you actually do turn 16 a few years from now and this or any test may not just be hard but nearly impossible, when your answer won’t be an uncomplicated, “I know.”

For now, though, it is just that simple, just something silent and shared, just a moment like so many that we share all the time but hardly notice at all. We both know you have a disability and there will be more to say on that another time, when we’re both ready again, when, like every other thing I try to teach you, the repeating will help. Sometimes simple, sometimes complicated. For now, though, mom, keep your eyes on the road. Conversation ended for now.

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