

you say so



What you see, what you get

My first strands of gray hair made themselves known during Mrs. Singer's eighth-grade English class. Actually, Mark Bostrom, the young man who would — in my freshman year — become my first official date, leaned forward to softly herald their arrival from the desk immediately behind mine: "You have gray hair. Did you know that?"

"Where?" I inquired, for I had not known it.

"Back here," he said, reaching up to move a section of hair near the nape of my neck.

I pretended to listen to Mrs. Singer and tried not to flinch when Mark — without warning — pulled out a strand. He handed it over my shoulder to affirm his discovery, and I looked with fascination at the evidence. Before I could formulate a response, he said: "Do you want me to pull them out? There are probably eight. Maybe more."

What!?!

I cocked my head just enough to let him know I had heard his offer, but not enough to attract Mrs. Singer's attention. Eight of them? He had counted? The thought fascinated me, but his offer to pull them out fascinated me even more. Obviously, Mark believed that women weren't supposed to have gray hair — that we were to rid ourselves



Photo courtesy Joy M. Newcom

Joy M. Newcom with her son Stross. Newcom has written a book "Involuntary Joy" about the lessons she has learned from being a parent of a son with a disability.

of its existence by removal or, possibly, concealment.

Too young to have peers facing similar propositions, the moment felt momentous: My 13-year-old body was aging prematurely. How was I to respond? What kind of woman I would I be?

I shifted my position enough to lean back and whisper a decisive answer.

"No," I told him. "Don't pull them. They're mine."

Then I turned, looked him in the eye and flashed a smile. He smiled back.

Thirty years and tens of thousands of gray and white strands later, I have not looked back. I am now in my middle 40s with hair color that defies my age. I'm not as old as some believe me to

be, and I'm OK with that. It is what it is.

In eighth grade, I had no way of knowing that this don't-assume-you-know-me-by-my-looks testament would help me identify with my oldest son, a young man of nearly 18 years who was born with physical and intellectual disabilities. His life-limiting circumstances

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have shaped not only his life's course, but mine. And from the moment I first laid eyes on him, the deepest part of me continues to cry out, "Don't regard him as less than anyone else. He's mine."

I certainly understand Stross is not "mine" in the most possessive sense of the word. I regard his life as mine to protect and guide. I also revere the wonder of who he is and regard him as a treasure to be shared with whomever can accept him for who he is: an incredible young man who lives nearly every moment with palpable joy.

As an infant, the extent of Stross' disabilities was nearly imperceptible, for others couldn't see he lacked the nerves necessary to walk, nor could they notice that he soiled ostomy pouches rather than diapers. Most of all, they certainly couldn't tell that he would grow up only possessing the problem-solving skills of a 7-year-old. It took his father and me more than a decade to discover that ourselves.

Unlike that day in Mrs. Singer's classroom, no one leaned forward to tap my husband and me on the shoulder then whisper the revelation of Stross' rare birth condition into our ears. Our knowledge came as suddenly and surprisingly as the moment of his birth. Then, as with the moment of clarity when I accepted my gray hair, I accepted the reality of Stross' altered existence by answering a question. This time the question was: "What kind of mother am I going to be?"

Since the day of his birth, Stross has helped me define my role by living as a constant source of unadulterated joy; and his joy exists regardless of circumstance. It's a witness I value more with every passing year, and I continue to aspire to live as he does, taking in

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each moment as if it was designed for pleasure.

For instance, some legal papers arrived in our mailbox a few weeks ago, outlining the need for him to establish my husband and me as his legal guardians. As the papers clearly indicate, the action is necessary because his "decision-making capacity is so impaired that [he] is unable to care for [his] personal safety or to attend to or provide for necessities [food, clothing, shelter, medical needs] without which physical injury or illness may occur."

As I read the stark legalese, a renewed sense of grief swept over me, and I choked with emotion. My son was nearly 18. He should be anticipating new relationships with roommates and dorm-mates, not being asked to re-define his relationship with his parents by relinquishing his right to make certain life decisions.

When my husband noticed I had been crying, I held up the papers in explanation and offered a simple statement: "The guardianship paperwork arrived."

Stross snapped to attention and looked my direction with a face that beamed excitement. He sat taller in his wheelchair and lifted his hands with exclamation: "My lawyer sent me papers? Are those from my lawyer, Mom? Do I need to sign?"

I was momentarily speechless — just long enough to make the emotional trek from my path of self-pity to his land of endless delight.

He cued my response

again: "Do I need to come up there and sign my lawyer's papers, Mom?"

His repeated use of the term "my lawyer" brought an involuntary smile. This was about his life, and he owned it. He deserved a response.

"Well, yes," I said. "I guess we should just get these signed right now, huh? Why wait?"

"Yeah. Let's do it," he said, beginning to wheel up the ramp to our dining room.

Why indeed? Our life as a family is what it is. We have a 17-year-old son who won't be doing the same things

his chronological peers are when his 18th birthday arrives. In fact, he'll likely never keep pace with others his age for most of the things that comprise daily life. And that's OK. It really is.

Maybe I started to learn that lesson in eighth grade and I have my early strands of gray hair to thank. Maybe realizing that my life might not track like that of my chronological peers has helped me as a mom.

As Stross regularly demonstrates, you just have to claim the life you are given, and then keep moving forward. After all, what you see and what you get don't have to match. Sometimes what you get is far, far better.

Joy M. Newcom lives with her husband and two children in Forest City. Find out more about Newcom and her recent book at her Web site www.involuntaryjoy.com.

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