

1 *The Doug Moe's Interview*

This is an interview by Doug Moe, a Madison, Wisconsin freelance writer and reporter interviewing Steven Salmon, a Madison author with severe cerebral palsy. The interview covers Steven's life, struggles, how he writes using Morse code, his craft, seven books, and his fears about the ending of Medicaid. Should he live or die? What will happen to Steven without care? Questions are abundant with so little answers by the federal government.

1. Steve, let's begin with a little background for folks who don't know much about you. You were born with cerebral palsy, yes?

Yes, I was. I was adopted by my parents. When I was eight months Mom and Dad noticed my head was drooping, a doctor diagnosed me with cerebral palsy. An interesting note is the doctor was on the adoption board after my diagnosis all of the babies had to be checked before adoption. I changed a policy without knowing it. The doctor advised my parents to put me in an institution, but my parents kept me. We began our wild journey together with my sister who was adopted two years later. My parents had a dream of me being independent and fought for me. They would be very proud of me if they could see me now. I have a career and my own home.

2. While you were born in Ohio, you grew up in Racine?

I was born in Dayton, Ohio. My parents bought a farm in South Charleston, Ohio. It was eighty acres and we rented the land to a farmer. I spent my childhood riding tractors and combines. The house was part of the underground railroad. I have fond memories of the farm. When I was eleven, my parents decided to move to Lancaster, Wisconsin. My grandparents, uncle, an aunt, and cousins lived there. We would visit them often. Dad decided to start a business. We built a wheelchair accessible house in a meadow. Dad was having problems that we didn't see at the time. The second summer he would attempt his first suicide with me with him. I almost died. My parents separated for a bit. Dad seemed to be better. Mom gave him a second chance. Dad found an engineering job in Racine. We found a house near Kansasville. I would go to school in Racine because Burlington wasn't wheelchair accessible. My sister went to Burlington to school.

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Dad would attempt suicide about five times in a year. Mom, my sister, and I had enough. Dad went to California to visit his sister and never returned home. I went to high school in Racine graduating with honors. Mom and I would live there until my sister graduated from high school.

3. Talk a bit about your early education. You were in a special education class that wasn't very helpful? Nine disabled children and one teacher?

In nursery school I was evaluated by a psychologist who labeled me as mentally retarded. My parents refused to accept it. I was always asking questions about how things worked and were made. At the time I wore heavy metal braces in order to walk. The braces were draining my physical and mental energy. My parents took away the braces against the doctor's orders. They believed my intelligence was more important than walking. The same psychologist reevaluated me a year later. He allowed me to attend a special education class. We were taught how to read, comprehend, spell, and do simple math. Homework wasn't given unless you were bad. We had to wait our turn to be helped. Most of the time I stared at the wall or sat in the corner. I acted up at times. We were segregated from the rest of the school. Lunch was delivered to our classroom. All of us had different disabilities and were at different grade levels. The principal didn't allow us to be outside for recess because he didn't want to be liable if we were hurt on the playground. My parents decided I needed to put in regular classes before moving to Lancaster to see if I could handle it since I would be fully mainstream in the seventh grade. In the sixth grade I was mainstreamed for social studies and history. I felt guilty about leaving my disabled classmates, but I enjoyed the regular classroom. I had homework every day and I stayed after school to work with my special education teacher to work on my assignments for her class. I didn't have time to watch my farmer's friends work in their fields. I had homework to do.

4. In junior high, you begin mainstreamed classes?

Yes, I was fully mainstreamed in Lancaster. An elevator was built for me. I'm always the first to change things. When school started, the elevator was still under construction. So, I was in the special education room in the elementary school adjacent to the junior high school until

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Halloween. My teachers would visit me once a week. It was like Ohio except I had my own aide and more work to do. When the elevator was operating, school was very different and challenging.

5. How did that go? You wrote a novel about it called, *A Very New Day*, yes?

I didn't have the educational background to be mainstreamed. I was at different grade levels in my subjects. Science was new to me. Homework was more. Teachers were demanding with expectations. My temper tantrums didn't go very well in a regular classroom. I quit that. Girls didn't like it. I lacked the socialization of my peers. I would struggle in the seventh grade. It made me want to return to the special education class but my parents wouldn't let me. *A Very New Day* shows the story of my seventh grade journey from my special education class in Ohio. The book is out of print now. The publisher gave me a two year contract. The book didn't sell. The publisher canceled the contract.

6. Eventually you made the honor roll in high school?

In the eighth grade I met Mr Brown. He was my special education teacher who had cerebral palsy. Mr. Brown could barely talk, walk, and used a typewriter to write. Computers were still being developed. I dictated my tests to him. In the eighth grade I made the honor roll. I was lazy in the ninth grade and Mr. Brown said, "Steve, you're college material. Stop lollygagging around. You're going to have to work harder and longer than most people." I took it to heart. Mr. Brown showed me I could do anything. My special education teacher in high school was a dictator. She kept the special education classroom door locked. No regular students were allowed into the room. Boyfriends and girlfriends were broken up by her. It took her two years to figure out I liked three girls. I begged her not to meddle with them. They were friends who I like to say were girlfriends. I love the word, "Girlfriend." I still do. All I did in high school was homework taking college prep courses like Accounting. I dictated to her, my aide, or Mom. When I had an in class assignment, I had to return to the special education room to avoid disrupting my classmates. I

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graduated from high school with honors. I don't have any good memories of the time except for the three girls.

7. EWhen did you first set a goal of becoming an author? I know you majored in English from the University of Wisconsin-Stevens Point, yes?

After graduating from high school, I applied to the Department of Vocational Rehabilitation (DVR). DVR assists the disabled with training, education, and specialized equipment like computers. I needed to access a computer. My dream was to go to college. You must show DVR how you are employable. I was labeled unemployable. At eighteen I was shown the door, but I was a great guy. I sat at home for two years feeling sorry for myself, watching TV, and being angry at the world. One day Mom said, "I'll find a way for you to attend college, but you have to start reading. College students read a lot." It took me a week to read one *Sports Illustrated*. Gradually I began to read faster and faster. I started reading sports autobiographies. Rather than watching TV all day I read. One day Mom pulled out a book called *My Left Foot* by Christy Brown. Christy had cerebral palsy. He painted and wrote with his left foot. Christy experienced the same kind of problems I dealt with like the lack of an education, loneliness, and suicide. I laughed and cried while reading the book. One day I almost attempted suicide driving into a lake being mad at DVR, but I decided to prove them wrong. I used my anger to become a writer. After I finished reading, I said, "Mom, I want to be a writer and write a book." That's where the dream started. I was the next Christy Brown. Of course, it took time and patience to go to college. After my sister graduated from high school and went to school, Mom bought a house in Madison for me to attend Madison College. I was a part-time student taking six or nine credits a semester. I did well and loved school. Four years later I received a Liberal Arts degree, but I wanted a bachelors and learned how to write. A history instructor at Madison College asked me to read *Montana 1948* by Larry Watson. I loved his writing. He taught at the University of Wisconsin-Stevens Point which has a writing emphasis program. I was accepted. Mom moved and bought a house in Plover for me to attend Point.

8. Was it at Stevens Point that you first began writing?

My uncle found a quadriplegic woman who ran a nonprofit organization dedicated to finding computer access for the disabled in Chicago. I didn't go to school in the summer. The second summer in Madison Mom and I made several trips to Chicago to try a voice recognition computer. The first sentence I ever wrote was, "I am a writer." Mom bought the ten thousand dollar computer software called Dragon Dictate. I started writing my papers. My instructors allowed and gave me extra time to write essay exams at home. It was easier than dictating. I started writing at Madison College, but voice recognition was slow. I had to pronounce the command exactly the same way or I would have to retrain the command with Mom's help. Each word had to be spelled out each letter. That's dedication. It allowed me to develop my talent.

9. I believe you took several classes from the acclaimed novelist Larry Watson?

The first class I had at Point was English 200 with Larry. I was in awe. After the class, I went up to him to have my *Montana 1948* signed. I asked, "Are you really a writer?" He smiled. "I'm going to be a writer." Larry is a very quiet person, but he opened up to me. He taught Creative Writing at night. Mom would take me to the class when it was in the negative degrees for me to learn writing. I didn't have a computer that semester because I applied to DVR for a new computer, but DVR played games with me wanting to know if I could write, DVR didn't believe voice recognition worked, and they wanted me to take out a loan. DVR wanted me to go to summer school. I was dictating my writing to coeds at the library. Larry offered to buy the computer, but Mom bought it in April. In May I got the computer working. I spent June writing my forty pages for Larry. He gave me an extension. I took a Robert Frost class from him. When I returned to school in the fall, I was writing my own papers and exams. The last summer before graduating from Point I started writing *Buddy Why*. I asked Larry to help me. I had Independent Study with him. Larry gave me ideas and encouraged me. Graduation from Point was very emotional. I had doubts about being a writer and I didn't ask him if I was a writer. When I looked

at him coming off the graduation stage, we exchanged glances at each other. I took that as a sign. It was time to be a writer, now.

10. Was Mr. Watson a big help and an influence on you?

Yes, Larry has been there for me. He helped me after Mom's death and when I was given a thirty day notice by a former care agency for running over a care attendant. I had difficulty in finding a care agency to care for me. I went hungry often. Larry supported me through this. It was my fault. I would start living independently and he was very proud of me. I wrote an editorial in a Milwaukee progressive newspaper about Governor Walker's cuts to Medicaid and he praised my writing. My recent book with the younger brother is really my sister. She told me if I published the book she would "disown" me. I had four years of writing invested in the manuscript. I emailed Larry about it. He suggested making her character my brother. I agreed with his idea. After two months of changing the pronouns and names, I sent it to my agent who wanted more edits. I love my sister, but dumping a manuscript for someone isn't an option. I only go to Larry when I don't know what to do. We are friends. He is always glad to write a review for a new book.

11. What did you learn from him?

The first class I ever had from Larry he said, "If you want to write and get rich leave now., take finance. If you want to write, you are in the right place." He liked to say, "A writer can cover a wall with rejection slips." I didn't quite comprehend what he meant by that, but I do now.

I have been rejected by dozens of publishers in New York and literary agents, including my own agent. Rejection is a part of an author's life, but it still hurts. Larry is so humble about his work. People tell me I'm an inspiration after they read a book of mine. I'm just an author who writes for the passion of it. I think Larry does the same. He taught me to persevere through tough times.

12. Let's discuss how you are able to write. Can you talk about your method? I believe I know it involves Morse code.

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I use Morse code to write using my head. Fifteen years ago I started using Morse code to write. It took me two weeks to learn it. Dragon Dictate was discontinued and my speech had deteriorated. Also, I was writing and critiquing papers. Morse code allowed me to edit, write more, and surf the Internet. No retraining commands. I have a metal contraption with red and yellow buddy buttons that goes on the back of my manual wheelchair. The two buttons have wires which connect to a blue box called the Tandem Master. Another wire goes to the USB Port. My attendants place the contraption on the back of the wheelchair and leave me to write for hours. Morse code enables me to be completely independent allowing me to handle my word prediction program called CoWriter. CoWriter has a word list. I begin to spell a word and when I see it I choose the number. CoWriter then puts the word in the sentence. I start spelling the next word. When I put a period at the end of a sentence, CoWriter automatically places two spaces at the beginning of a sentence. That's how I write.

13. Your mother, Mary, was a great champion of yours. Please tell us what she did for you and how much it meant?

Mom devoted her life to me. When Dad became ill, she held the family together. Even before that she fought battles for me to go to school and take regular classes. I'm sure it was her decision to have Dad leave to go to California, but we couldn't take it anymore. Mom worked part-time while we were teenagers. Mom put me through college herself moving to Madison to Stevens Point, and back to Madison. Buying houses and computers. She didn't have a break or complain. Countless tasks such as turning pages, writing, editing, shoveling snow, washing soiled clothes, cooking, feeding me, and taking me back and forth to class. I remember being sick and going to school. Mom picked me up and I vomited when I got home. After that, I read until eleven before going to bed. She saw my determination, stubbornness, loneliness, and selfishness. Moving to Plover for me to attend Point was one of the biggest sacrifices she made for me. After graduating from Point, we didn't know what to do or live. I just wrote. We stayed in Plover for a year after earning my degree. Some of my former instructors at Madison College

hired me to critique papers and we lived in Poynette for four years. When the instructors had papers, Mom drove me to Madison to get and return the papers with my critiques. She applied for services in Columbia County, but there was a waiting list for services. They wanted me to live in a foster home and work in a community workshop. Eventually we moved back to Madison to live in the Cherokee apartments. We lived in a condominium for ten years until she died. Mom was a strong woman. I was spoiled by her and took her for granted.

14. Your mother's fatal heart attack in 2015 was devastating. You wound up writing about it in a memoir, *It's A New Life! Mom Is Gone*. Can you talk about how difficult her death was for you?

Mom did everything for me. In one night she was gone forever. She was my confidant. Now I have to grow up. My family stayed for three days before returning home to their lives. Then I was on my own for the first time of my life. I had to get used to having others care for my personal needs. Having women washed and assisted me with the urinal was all new to me. I was very modest, but that was thrown out of the window. Then I had to make all of the decisions from what to eat, when to go to bed, get up, what to wear, and decide what I wanted to buy for groceries. Four months before Mom died I went to a lawyer to have the power of attorney turn to me. I was lucky that I did it or I would have been a ward of the state. I became a man overnight. In a month I would hire a care agency, choosing a home, moving, adjusting to having two roommates, and burying Mom. Then I wrote my will, set up a trust fund, arranged my funeral, and started to write again. It was exhausting. I was numb, hurt, and confused, but I made it.

15. It's now a decade since she died. How are you coping?

It is unbelievable how time flies. I'm independent because of her. She would be thrilled to see what I have done. A career and my own home. It scares me some because I know I have a limit of time to live as the years go by. I will always miss Mom. There are a few people here today who took care of me when Mom died like Jenny who I dearly love. And of course, Tim, who I drove nuts with my emails complaining about the staff after Mom died. They listened and

understood, but now I just live my life. Care attendants come and go, but my friends will always be here for me.

16. Before we get to your most recent novel, *Why Did It Happen*. Please talk a bit about how your living situation is currently. I know you have had ups and downs with caretakers and government regulations. How do things stand now?

Two years ago I started living independently. At the time when I was given my thirty day notice I applied for an apartment with Movin' Out which assists the disabled in finding homes. I asked for an apartment under construction. After I found my current care agency, I lived in the group home for four months. On May 1, 2023 I moved into my apartment. I love it. The apartment gives me privacy to write, create, think, and sleep. The group home was difficult to live in at times. I couldn't have a woman come to visit me in the resident home even to socialize. I have manly needs. Sometimes I have a female visit. This is important to me. I have made mistakes with care attendants in the past. Some attendants bring it up to me. I can't undo what I did years ago. I'm living in the present. Caring for an author is hard. I know that. Attendants come and go, but some won't ever forget me. Ten years of living with attendants and sometimes I forget who they are except for the special ones. I have been hurt by attendants saying awful things, but I have done it too. It is human nature but it isn't an excuse. Also, I have to deal with constant reviews by the State. My services have been denied in the past for not working or having too much money in my bank account. The State does a Medical Assistance review periodically to determine if a disabled person is still eligible to receive services. People with disabilities can only make \$900 a year and have \$1,250 in their bank account or their services will end. I can't find a writing job paying \$900 a year. Jobs like that for me don't exist. I'm a full time author. Luckily my care team found another care program which doesn't require me to work. People like me need to pursue their careers, not work Mickey Mouse jobs. My financial company which pays for my bus tickets hasn't even though my budget plan calls for six booklets of bus tickets a month. I have to stop everything I'm doing to write countless emails to the financial company

which doesn't respond. Then I have to pay for the bus tickets with my social security. There are always problems taking my time away from my writing. That's how it is. Now I have to hire another financial company.

17. Are the government cuts proposed by the new administration a large worry?

Yes, the president says, "He will not touch Medicaid, Medicare and Social Security." Congress is actively working on passing the elimination of Medicaid, Medicare and Social Security. Once the bill passes the president will sign it. It is another one of his lies, but this lie will kill two million disabled Americans in a short time. I know my care team thinks I'm overreacting, but you don't replace \$880,000 without a lot of suffering, pain, and sadly death. I have written editorials in newspapers, emailed all of the Wisconsin representatives, Governor Evers, and the president about the real life consequences with the ending of these entitlements. There is no plan in place to ensure the lives of the disabled. People with disabilities, bus drivers, job coaches, and caregivers are in for a rude awakening in a year. No bus, jobs will be eliminated, and slowly care will decline putting lives at risk. Death will happen. No Medicare means no wheelchair, prescriptions, doctor's visits, or hospitalization. No social security means no food, rent being paid, and entertainment. How do you explain this to an autistic person? Their lives are their jobs. That's all they have. For me I can't go backwards. I have fought for this life. Going back to a group home isn't an option for me. I would be unbearable to live with and be cared for. Anger would destroy me. Without the bus I won't have my friends. I go out to escape my attendants sometimes. An author needs to experience life and needs space to think. There is nothing like sitting at a bar talking sports with a guy or dancing with a woman. In the summer I sit on the terrace writing in my head looking at the lake. An institution isn't a place for an author, but I'm considering it. I shouldn't have to make these decisions. Suicide is on the table. If I can't live, then I don't want to be here. I need my friends. Then the president decided to withhold Social Security payments in May due to fraud. I and other disabled people rely on our SSI benefits to live on. These entitlements have so many reviews to prevent fraud. It is just easier to say than

saying, "We have to reduce the budget deficit and give the upper class a tax break." The president doesn't want to be a bad guy. He will say, "The American people want this," making Congress the scapegoat. The president knows exactly what he is doing. During COVID I lived a year in seclusion and I can't go through it again. With this there is no end in sight. What really bothers me is I won't ever live with her. She is the only thing I want. I blame America. My words will live on.

18. Are you still active in advocating for the disabled? I know you've appeared at the State Capitol in the past?

Of course, I am. My voice and words are more important than ever before. Sadly the news media and our representatives have turned a deaf ear to my words. They are swamped by letters from other disabled people and advocates for people with disabilities. So, I have started publishing on Substack. For those who don't know what that is. Substack is an online community for writers to publish their work and have subscribers read what I write. Eventually I will ask people to pay for my writing, but for now I'm trying to create a following. Hopefully I can change some people's minds that way. I haven't really used social media before, but it is time to generate awareness more often. For fifteen years I have written a blog about my life. It shows the life of a man with cerebral palsy. My blog will be my legacy. Yes, I have appeared at the Capitol for Disability Advocacy Day. When I go, I have my own agenda advocating for the right for the disabled to earn a living. That's gone now. I'm thinking about sitting at the Capitol protesting against the elimination of the entitlements to show people we are making a grave mistake. I have to do something. This is not America. Special education is going to disappear with these endings of entitlements. The world needs more Steven Salmons in it.

19. Let's get to *Why Did It Happen*. Talk about the inspiration for the new novel?

I wanted to write from a different point of view. I have always written about my life. The news media isn't interested in my story. So, I thought what if I wrote from the perspective of a sibling of a disabled sibling. Not many people who are disabled could do that. My intention was to

generate interest in New York publishers. Unfortunately, after four years of writing and countless revisions my agent decided the book was inappropriate for teens to read due to the multiple suicide attempts. She was going to send it to New York, but a week later she decided against it. That was heartbreaking, but I would publish it myself. That's an author's life.

20. We don't want to give away too much of the plot, but can you briefly discuss it? It's about two brothers, Caleb and Troy, and there is trouble in their family. The boys are twelve and thirteen, yes?

That's correct. The middle grade book is about a father's depression and Caleb helps to take care of his older brother, Troy, who has cerebral palsy at times. Caleb tells the story of the family's love and sacrifice.

21. Their dad has some issues, right? He's bipolar?

The father is my dad, who suffered from severe depression. We didn't know it at the time, but there were signs of it that my family didn't see. Then one morning he took an overdose while I was with him. We took a joyride and he almost killed us. Our family would go through five suicide attempts in two years. The beloved Dad couldn't be trusted anymore. I would go everywhere with him, but after the first suicide attempt I wasn't allowed to go anywhere with Dad. Mom, my sister, and I would have enough after Dad didn't come home from work one evening. He was discovered in a park behind our house. What was he planning to do was Mom's question? Luckily she made him get rid of his guns before that time or he would probably have killed us. After being up all night and going to school the next morning it was decided dad would go to see his sister in California. Dad would attempt suicide a few days later and never returned home. At times he would call us drugged out of his mind. He died one Christmas Eve ending the long journey. It is sad since he didn't get to see his kids grow up. My sister and I adored him.

22. Was this book harder or easier to write than the others, or about the same?

It was harder than most. I had a good working first draft about three years ago. Then I met an editor, who worked for Tina at a writing retreat. He edited several manuscripts for Tina's authors which were published in New York. He tore it apart. I rewrote it in a month. Tina said it wasn't ready to send to publishers. I kept working on it. Then my sister told me to not publish the book or she would "disown me." I emailed Larry about the problem. He suggested making her my brother. For three months I changed all of the pronouns. Tina read it again but no. So, I hired another editor who tore it apart and I revised the manuscript. Tina said, "It needs more work." Last summer Tina would work closely with me editing the manuscript. Around September Tina was ready to submit it to publishers in New York, but she changed her mind. It hurt me. I moped several days after the rejection. My staff didn't understand, but they gave me space to think. After talking to some authors I decided to publish the book myself. New York won't ever happen. I'm still an author.

23. Please talk about the feedback you get from your books? Are you able to engage with readers through email? If so, is that rewarding?

I used to receive emails from readers occasionally. A reader from Russia emailed me once. That was neat. And some other reader emailed me from Europe. I haven't received any readers' emails for a few years. I haven't published a book for a few years. My website changed its name without me knowing it. That's solved now. Sometimes I will be out in the community and someone will say, "That's Steven Salmon, the author." I love that. Once a couple recognized me on a snowy day. I often talk to people at bars and my career comes up. People Google my name and are surprised to see I'm an author. They might buy a book. My speech is difficult to understand, but when a person is patient I love to talk. My books and writing open up the world to me. I'm not "dumb." I become a normal person. The electric wheelchair and cerebral palsy disappear. When I'm with a woman, I turn into a man with a career. It is magical. It gives me the energy to keep writing.

24. Can you tell us if you are working on any new writing projects, and perhaps describe them?

I have another middle grade manuscript about a man who is an author with cerebral palsy who suddenly dies. His nephew decides to write a paper about his uncle discovering the true man of his uncle after being cut off from him. Also, I'm writing a romance novel about a man with cerebral palsy who is an author who meets and lives with a woman. After being hurt by women, Jack finds Lisa. They are friends at first, but they fall in love. Lisa moves into his apartment opening new problems while creating a new life. He publishes several books. They travel to places like the Grand Canyon making memories leaving the past behind. Suddenly Jack develops cancer. Lisa holds his hand telling him to go granting Jack's last wish. She moves on with her life but never forgets Jack.

25. You have done remarkably well in life and as an author. Do you still have goals that you've yet to achieve?

I want to publish ten books. New York was a dream but it won't ever happen. I would love to have a book deal. That would be a challenge. My agent is working on it but she has disappointed me. Ten books published would leave no doubt that I wasn't a fluke. Being interviewed by Susan Siman on Live at Five has been a dream of mine. That won't ever happen. I would like to meet her once. And of course, her. She is the only thing left now. I need to find her. She is always on my mind. The females in my life reassure me I will find her. Time is short. At least I have my friend Tammy and my sisters from college. I still want that special lady in my life. She is near. Hopefully we meet.

26. Is there anything else you would like to share with us this afternoon?

I just want to live my life, but the future isn't mine. Two years ago I thought everything was going to happen. And now it could all end. Well, thank you for coming. Please help yourself to some cookies. Thank you, Doug. Stay tuned for another book next year.