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A Father's Story about Movement

BY BRYAN A. BOWER

I feel like I am waking up from a long, long dream, like Rip Van Winkle. Or awakening at my easel in a dimly lit European alcove in the middle of a cold dark night. Or waking up near a flickering candle like artist Rembrandt van Rijn or Peter Paul Rubens of old might have done. It is like a spooky déjà.

For now I too am an old artist. Ever searching for relevant meaning and purpose for my art expression, just as I searched a lifetime ago when my son was born. Now I am an old father, coping with my own advancing disability. Now I am an old man, having spent half his life caring for a son with a disability. My son has his own life these days and I'm left with many mixed feelings of regret and melancholy. Why couldn't I have fared better during my life path fulfillment? My art seems adequate enough.

The writing of this article stirs my emotions deeply as this chapter of my life really began on the 28th of September, 1994 when my little boy was only 6. On that day in September I received a letter from *Exceptional Parent* magazine saying that they would NOT be able to use the suggested article I had submitted at that time. It was an article about a story, my son's story. *Pillowdown* is an allegorical adventure tale with cute illustrated characters, where all the players and events directly represent non-fiction counterparts and events analogous to my son's medical condition. My son's condition? Spina bifida. The story's full name? *Pillowdown, the Mystical Country*. The telling of this story began 23 years ago, the conception of it even sooner. I have been given permission by *EP* magazine to resume telling it to you now. My journey has gone full circle, arriving here, at my last stop.

Movement has many applications and definitions; did I arrive too late at my scheduled destination for anyone to greet me? Or give ear to my message?

CHAPTER NOTES ON PILLOWDOWN

The overall theme of *Pillowdown, The Mystical Country* is movement. The evil Spinasaurus personifies the terrifying & crippling effects spina bifida can inflict upon children. Nuro the Bumblebeast represents the gifted neurosurgeons that intervene with precise corrective procedures on children improving their mobility functions. Movement. Pure Zolden shoes represent the event my son experienced at three years old. When AFO's were first placed on his legs, my son miraculously leaped up and ran around the kitchen dinner table releasing pent up desire for movement! It was amazing, thrilling the heart. For since birth he had only "creeped." The Pillowdown Birds on Mt. Roonwren represent the freedom that movement can give to the human spirit, loving angels living on a higher plain and giving gifts to all those below. The luxurious pillows and featherbeds represent security and safety. Roonwren Mountain represents comfort and solace after heartbreak and loss. Home.

Pillowdown, The Mystical Country is a short chapter book with illustrations. It has 10 more chapters about the length of the first

EXCERPT FROM *Pillowdown, the Mystical Country*

CHAPTER ONE

Pillowdown Birds & Roonwren Mountain

Once upon a feather, in a place with perfect weather, far away but not so long ago, at least the wise men tell me so, there was a land known as Pillowdown. Pillowdown was a mystical place of peace and harmony. Pure sparkling lakes and rivers flowed around and through Pillowdown, finally finding their way to Roonwren Mountain. A myriad of exotic and rare animals flourished in this land, not the least of which was the Dinosaur-Dragons. Near the base of Roonwren Mountain was the small quaint village of Pillowdown the Town, the capital of Pillowdown the Nation.

Pillowdown Nation,
Pillowdown Tribe,
So proud to live,
So proud, here's why!

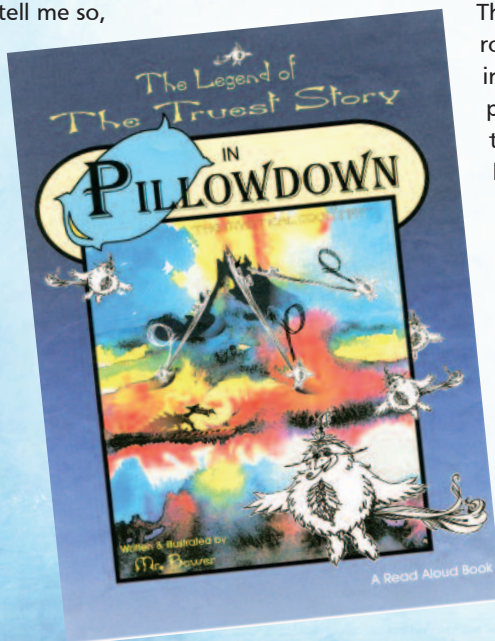
Their village was renowned in many distant lands for its fine, fluffy and luxurious

featherbeds and pillows that were made there. This village was the pride and commerce center of the Pillowdown Nation.

These pillows and feather beds were made with the subtle feathers from the Pillowdown bird. These miraculous birds lived

high atop the Peak of Roonwren Mountain. Their feathers made them so fluffy they could roll up and down the mountainside like insane yo-yo's and never be injured! Their prehensile tail feathers could grasp and hold to a branch or rock and stretch like a rubber band. Once a Pillowdown bird began yo-yoing up and down this way it could yo-yo for hours, even days.

Every time Pillowdown birds would yo-yo some of their feathers were knocked loose and fell out, making room for the new ones that grew back almost instantly. Many of the children from Pillowdown town would go upon the mountainside and collect these wondrously fluffy gifts that were used as down for the pillows and feather beds that were made there. This is how the name "Pillowdown" came to be.



two. With a total of over 2000 entertaining words that are easy for children to understand and follow, Pillowdown is really a story about the indomitable spirit of a family's love.

I want to change direction a little bit. Let me combine my own personal bouts with multiple sclerosis and how it affected my physical and mental movement, fueling inspiration for another storybook, *Little Miss Blue & Mr. Red Who?* I'm sorry but I am just a grown-up child searching for answers as to why? This is a funny, funny story inspired by my own handicap this time. I used my art to try to keep good humor, hope and mental health alive by creating good things from bad. Mirth celebrated when circumstances were trying! Movement.

Resurrection of a renaissance man, again and again. Relapse, remit. Relapse, remit. Breath in, breath out. Breath in, breath out. Succeed & fail. Laugh & cry. Despair, rejoice, worry & rest, trials then peace. These are the voyages of my star life living with multiple sclerosis. What



makes matters worse is that my mind's vision is clear but my body is unwilling to cooperate. Then fatigue weakens my mind also! FRUSTRATIONS GALORE! I can relate to many others who may have experienced this same dichotomy of experiences and emotions. I had my first major exacerbation and introduction to a newfound friend; multiple sclerosis in 1994. "Exsqueeze me, newfound friend did you say?" More like a taskmaster or a prison guard that now resides with me, 24-7. My taskmaster guarantees that everything physical has extra weight added to it; under the lash of fatigue. This is when I was most concerned about my son's future. He was born with spina bifida in 1988.

In 1994, under extreme duress and fatigue exacerbation causes, I attempted to publish a children's book using my drawings, my son's condition and our struggles for a plot. It served as a therapeutic remedy. Its plot is about a dinosaur-dragon that terrorizes a child and her father. The child became the liberator to those threatened in the story

as the Spinasaurus was out of control and roaming free without restraint!

CHAPTER TWO ZoeBell Fair & her Long Zolden Hair

There was one little girl that couldn't go "Quilling" on Mt. Roonwren to gather feathers with the other children. Her legs and feet were too weak to walk up the steep mountainside for she could only creep. This made the little girl very sad. Her name was ZoeBell Fair with the Long Zolden hair. She did not have royal blood, but no Monarch could have been more regal and true. Her father worshipped the ground she lived on. She is all he had in his simple life along with his work and deep dish Lotzarella Quizza, with red, orange and yellow peppers. Lots of Lotzarella cheese sticks with hot dipping sauce! And a bottle of Zoca-Zola to finish it off rather spicely!



At the beginning of her life she had been injured by a renegade Dinosaur-Dragon called the Spinasaurus. This Spinasaurus made a hole in her back. This injury was very grave; it might have left her totally paralyzed had not another, but friendlier, Dinosaur-Dragon called a Bumblebeast, come to her rescue. This Bumblebeast closed her wound with his wonderful healing light. This Bumblebeast's name was the amazing Nuro!

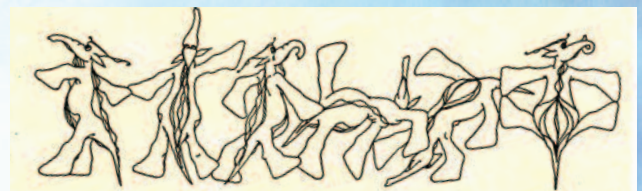
The Spinasaurus that did its dirty work was the nastiest kind of dinosaur-dragon. He was a huge ugly beast and a coward that only lived, for some odd reason, to hurt children. Hurt children he did, some much worse than others. No child was really safe as long



as the Spinasaurus was out of control and roaming free without restraint!

ZoeBell was a dreamer. She lived in a tiny cottage with a deep, deep well and a large old barn on the

outskirts of Pillowdown town with her father. He ordered deep dish Quizza shell whereby he fed them both real well. Father was honored as Pillowdown Nation's most skilled metal smith! Working with steel and copper and gold he fashioned most of the implements and hardware needed for the inhabitants who lived in Pillowdown town. These inhabitants were known as the Pillowdown Quillers, and their children as the Pillowdown Quillees!



Father was gifted at his craft 'tis true! When the village doctor suggested to her father that ZoeBell needed some sort of leg supports to help her walk better, her father became driven by the obsessive task. A miracle to perform! That very hour Father put on his white leather apron and went to create magic in his smelting workshop. The goal of his magnificent obsession was to fashion something, anything that might help ZoeBell his precious daughter to walk. He designed leg supports and shoes made of 99.9% pure Zold! Zold! Zold! Pure weightless Zold!!

[End of Chapter Reading]

that ended with a happy resolution for all concerned. Even the villains were spared. I submitted my manuscript to Exceptional Parent magazine and the editor was delighted. That person changed their mind after much negotiation. You'd think that I would've given up on the thought of being an author of a children's book. Time lead my unremarkable life's journey forward with my taskmaster accompanying me every minute of my way.

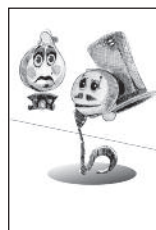
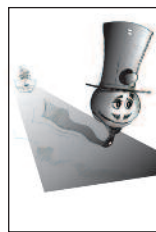
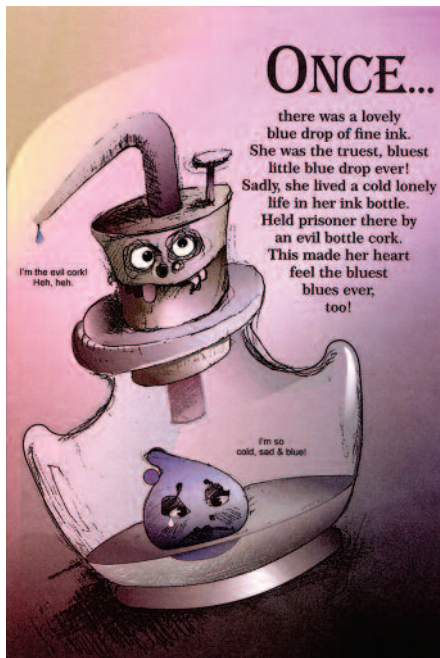
I moved nearer to a children's hospital in another city for expert treatment for my son. One ray of hope for my mental health: I still had my magic pencil to carry me through those times of uncertainty. In my life before MS, I was a prolific artist working in many mediums: drawing, metals, silver, oil painting & piano to name a few. My music and art career were severely hampered by multiple sclerosis. Adding another advanced degree in

effortlessly interacting with no sign of fatigue.

Their innocent courtship and drippy love affair reflects the desires of every person, with a happy ending. An ending those children and their parents can identify with. The activity version has an additional 35 pages of educational fun material that will keep children busy for hours after its reading. These activities are suitable for all children at many cognitive levels.

EPILOGUE

Today my son is 29 years old, has bought a home and is working as proofreader for a sub contracting company that services the local air force base. He is my hero. My example of how someone with severe disabilities can overcome their own obstacles and limitations to reach and attain their goals. •



BOTTLED UP: Details from *Little Miss Blue & Mr. Red Who?* A little blue ink drop is held prisoner in an ink bottle by an evil bottle cork that represents multiple sclerosis, the gate keeper of my body. Tormented every night by cork's nightmarish rhymes, Little Miss Blue finally escapes from her bottle prison.

1997 was the most logical choice for someone with my new physical limitations. Down, but not out for the count, I was forced again to retire from my new teaching profession after only six years. Hello taskmaster my loyal companion, you're acting up again I see. How have you been? Busy? I hope not.

When I had to take disability retirement from being an elementary art teacher in 2004, I pondered the thoughts of paralysis and powerlessness once again, lamenting, "Having a physical handicap is like being held prisoner in a bottle." So I set out to write and illustrate another allegorical fantasy inspired this time by my life hampered by multiple sclerosis. This storyline was about a little blue ink drop held prisoner in an ink bottle by an evil bottle cork that restricted her movement, her self determination. She is tormented every night by cork's nightmarish rhymes and nightmare mop's nightmares. By accident Little Miss Blue escapes from her bottle prison.

Cork represents multiple sclerosis, the gate keeper of my body. Mop represents fatigue (look how he torments Little Miss Blue!) The ink bottle represents my damaged body holding my spirit captive. Understand this; a little drop has no hands, feet or legs to worry about (unlike MS sufferers that do). They just hover around

ABOUT THE AUTHOR:



Bryan A. Bower: "I create custom games and toys that match a child's particular cognitive level or physical deficit. My philosophy is this: ALL KIDS NEED TO DO IS HAVE FUN! ALL KIDS ARE KIDS FIRST! The trick is how do you present the right vehicle for fun that overcomes deficits? My hope is that this exposure of writing for *Exceptional Parent* magazine will help me secure large book and game orders for Reewob Publishing to thrive and prosper. Where are Walt Disney, Dr. Seuss and Quick Draw McGraw when I need them the most me wonder? Ha! Ha!"

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HELP!

Is there an angel out there? My business plan is to provide illustrated stories, games and toys for a child with special needs. Toys and stories that everyone else wants! Writing exciting stories featuring cute characters that cope with certain deficits can go a long way toward promoting inclusion and self worth in a child.