

Breathing Through a Straw

Cody and I

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Mark William Sheehan



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**‘In the 1950s, children
born with cystic fibrosis
were not expected to live
long enough to attend
elementary school.’**

*Boomer Esiason, former American football player and
cystic fibrosis campaigner*

Prologue |

As long as I could continue adding pieces to Cody’s story as a ‘work in progress’, I could avoid having to look my life in the eye. Writing this book was, for me, like the tale of the little Dutch boy, who put his finger into a small hole he’d created in the dyke. As long as I kept my finger there, held onto our son’s story, I could avoid the emotional floodwaters, and the breaking of the dam.

Like that little Dutch kid, I’ve clung to the wall, petrified to discover what might happen when I finally do pull my finger out ... looking back, I also may have been, alongside our son, breathing through a straw.

Just keep running, as fast as you can!

As a kid, I won a whopping \$10 bet from a neighborhood bully when I flew across the Manhasset Bay ‘pluff mud’ behind our home. The run could only be attempted during a moon tide. Writing daily about Cody’s life was the same

for me: as long as I kept flying across the slick, foul-smelling surface, I could avoid sinking into the crap-like gunk.

I made it to shore, covered in repulsive phlegm, and made a 'double-back dare' to the bully who'd baited me: he had to follow my path, or lose face with the other kids along Bay Driveway. When he faltered about 50 feet from shore, he quickly sunk to his knees. The more he wiggled and shook himself about, the deeper and deeper into the pluff mud he went. It was approaching dusk and the tide had turned when we kids on the shoreline realized our local bully was in serious shite. He was 20 yards off and screaming out for help. Joanie Lindner and my kid brother Chris started to cry. We mustered boards and planks and shimmied out to him on our bellies with a rope to tie under his arms. The kid was in shock by this stage, knowing where he was positioned would shortly be under five or six feet of water. With all of us toting, we dragged him to the shore, minus his shoes. The kid was so horrifically ripe, nobody would go near him. The small crater he'd made in the pluff mud was quickly filled with water and vanished.

I feel like that now. If I can just keep running, in my head, I won't sink.

I've always been a sprinter by nature, exploding with bursts of love, and productivity, and gusto, followed by decompressions. I completely collapse on the kerbside, depleted, until I can catch my breath and start sprinting again. My 'old man' used to say I was 'blessed with a short attention span'. When I do get going again, it's often in another totally new direction, along an altogether different path. This personality trait is not conducive to long-term

relationships, marriage, or chronicling a tale that runs into decades in the telling. I find it near impossible to revisit or edit anything I've put to paper about my son Cody's journey.

| Thanking You

I sat emotionally devastated, in the office of my publishers, because after more than 20 years of happily calling New Holland Publishers *my* home port, I had all *three* of my proposed book pitches rejected. My pulse went into overdrive, my palms sweated and I dreaded what was coming next.

I knew beforehand that wonderful publishing houses, doing fabulous books worldwide, were closing up shop by the month. Times were viciously tough. But I'd never imagined it would happen to Fiona, New Holland, and *me!* I simply assumed, that Fiona Schultz, powered by her enormous energy and leadership, was going to save us all: our very own Mother Teresa of real, printed books. (She'll scold me for this analogy, but I've bribed my editor in advance to kindly leave it on the page.)

In defending her rejection of my three proposed titles, Fiona said that I'd boldly promised her a bestseller when

we first met and my bestselling *America Over Easy!* travel guides 'didn't count'. In her view, I'd yet to deliver the good oil on paper 'as promised'.

Our fabulous Fiona slid a contract face down across her boardroom table, saying, 'This is the book I want this year. It will be the hardest one you have ever done for us. Feel free to take all the time you need ... I'll expect it in six months. I want to release it on Father's Day.' The contract was for the story I'd wanted to write for years, and never had the gumption to slip shyly into Fiona's new-books suggestion box. I held back my tears, until I saw hers. Outside her glass office, Lesley, Fiona's good friend and PA for more than 20 years stood crying herself, while offering up a box of tissues.

The 'working title' on the contract read: 'Cody and I: Breathing Through a Straw'.

Dedication works wonders

I truly believe our Cody has come this far, and done this well in large part, because of his spirit and the dedication of his mother. It might be a little bit too far into the telling of this story, but this book is dedicated to Bridget Willis Sheehan, our remarkable son Cody, and to all the other cystic fibrosis kids out there, who continue to press on against some seriously shitty odds.

Today, there are some very smart people within striking distance of a cure for cystic fibrosis. And almost daily now, hope for new treatments and medications is shared worldwide, adding more fuel to the 'find-a-cure' fires. Parents and loved ones, throw emotions and money at lawmakers

Home Is Where the Heart Is!

and health-cover providers by the bucketload to change the lives of CF sufferers. The new treatments and medication band aids are getting better by the week and are available to more kids who need them than ever before. The fighting is far from finished.

On the day our Cody was diagnosed, the average life span for a cystic fibrosis kid idled somewhere between 9 and 12 years. Cody is my hero: he's crossed the Rubicon into his thirties, with the help of some remarkably wonderful people. This is Cody's story, and he's given me carte blanche and the blank pages to tell it unencumbered. When I told Cody about 'our book', he said he was 'all-in', but he refused to see the words I'd written until we cut the ribbon at a proper book launch. He hugged me, saying whatever I wrote was going to come from a good place. The kid has a great deal of faith in his father.

In turn, Cody said he'd write 'his bits' and Fiona's team at New Holland Publishers could drop his words into place depending on where they best found a nest alongside mine. Or, better yet, make another book of his view! Our dual

apologies in advance for mild redundancies that pop up in our story. Any exaggerations, discrepancies or inaccuracies are all mine.

My son and I made a pact: to not share, or openly discuss this story, until there was no time to turn back. We also agreed that neither his mother, nor his siblings and extended family would have an inkling beforehand.

Cody's story is powerful, and his perch and perspective for telling it is nothing shy of inspirational. Before hitting the print button, Cody asked to have a few of his bits removed for sharing later. When he turns 80! Cody's found his own voice and has many, many more chapters to complete. It's just how the guy rolls. Keep your eyes peeled for his story; he's a wonderful work in progress.

Cody's only caveat

Cody's only proviso to this arrangement was that if our book was to feature photographs, he wanted to have control over any images to be used in the book; he didn't want to discover any full-frontal, butt-naked baby pictures of him in the bathtub with his siblings! He knows me well ... he asked his mom for help when it came to collecting the pictures. Bridget has lovingly documented our entire family journey.

A tear-jerker? Cody won't have a lick of it!

*'Time spent laughing is time
spent with the gods.'*

Oriental proverb

Even if I wanted to make Cody's story a tear-jerker, or engage the reader in pulling heart strings, I'm not sufficiently

equipped with the writing skills to pull it off. And more to the point, Cody wouldn't have a lick of it.

Cody's story is not like that; from the first contagious belly roll of laughs that popped out of this amazing kid, he set the stage and the tone for everyone who's ever known him, or loved him, or simply enjoyed a brief encounter with this fabulous fella. As a parent, I'm permitted to have a slight bias. Sue me.

Hanging around our son is a bit like taking non-toxic, turbo-charged Red Bull cleverly camouflaged in a quart or two of caffeine: without any of the negative side effects. He's funny, and charming and motivated and, honestly, half the time I don't know where he draws his enormous energy from for pressing ahead with a smile. I light up like a Christmas-tree ornament when I'm around the guy. Cody saved me: most people who know our story mistakenly see things the other way around.

Cystic fibrosis is not contagious – Cody's remarkable lust for living fully *is!*

Childhood – notes in bottles

In 1969 America put a man on the moon, and I drew the not-so-lucky number seven in the US draft lottery for the Vietnam War. My slightly older brother David merrily drew number 330-something the year before. That same year, the planet learned about a magical musical weekend of peace during Woodstock at old man Yasgur's dairy farm. I had a lot to say about it all, but I was unsure of the power of my own, high-pitched and squeaky voice. To let off steam, I began writing haiku-like entries, dating and signing them,

Getting Started: Charleston, South Carolina

and sealing them in bottles. I'd stockpile a dozen or more and then randomly launch them at different shorelines and in surrounding waters to be taken away on the tides. I was writing to an unknown audience of one, whom I'd most likely never meet. It was before 'recycling', and I used bottles that would have layered the Atlantic surface. Most of New York's garbage was being towed and dumped by ocean barges.

I kept a nautical-like logbook in an old ringbinder and recorded the date, the place, tide, and my emotional weather report on the day. I called them my 'float-a-notes', and like snowflakes, no two were ever alike. The places I launched my emotions over the years would make a pincushion of the world map, and those cleansing entries helped me beyond any shrink's sofa, drug, or bottle of grog.

There's a book in those bottles, if I ever get around to writing it. Nowadays, I just write notes to myself on my laptop, and call them by the same name. Some of them have found their way, sprinkled like salt and pepper, into Cody's story. Writing them about our son gave me the chance to put them 'out there' and then move on. Some days it was hard, just getting out of bed. Venting helped.

Unknowingly, I started writing *Cody and I* the day I cut the umbilical cord in Charleston, South Carolina, separating Cody from my wife, Bridget. Cody William Sheehan was the most magnificent thing I'd ever seen, created by my beautiful Namibian-born wife Bridget and me. We cried together for this child, counting, through our tears of joy, the fact that he toted the right number of fingers and toes. His limbs were nice and pudgy and Cody's eyes were clear. He inspected his new world and his teary-eyed parents for the first time as though he were sighting a cannon. Cody was taking beautiful, deep breaths, as he practiced using his lungs for the first-ever air outside his mother's womb. We watched him just breathe.

The nurse placed Cody on his mother's chest, while hospital staff morphed the antiseptically spotless delivery

room back into a hotel-like suite around us. Oxygen canisters, intravenous drip poles and masks, medical apparatus and other gizmos were all hidden away. You pay extra for this in America.

On the day of our son's birth, my wife and I had unknowingly granted Cody a death sentence. He has the worst genetic combination of cystic fibrosis genes, delivered to him through many previous generations by his genetic family tree. He was created with a many generational Molotov cocktail tossed in that would kill him.

We wouldn't learn this until our son was six months old. Hospitals didn't test for CF at birth in the USA, as they do in many other countries. I'm not sure to this day why. It's a very simple test of salt content – one of the most common elements known to mankind.

Little did I know then that years later I'd become almost immune to the scurry of hospital nurses, interns and intravenous drips, the movement of dinner carts stacked with plastic food and trays, bland blue gowns, and doctors: a seemingly endless ebb and flow of doctors poking our Cody. I've come to detest fluorescent overhead lights.

1989, yep! 'We're pregnant!'

Enlightened with the news that 'we're pregnant', I openly celebrated the fact that I was going to be a father. Inwardly I was scared shitless.

I'm not qualified to speak for other fathers, but I can tell you, when Bridget said that she was pretty sure she had a bun in the oven, I silently went into an emotional tailspin.

While my emotional exterior fuselage appeared to be elated and cruising comfortably at 35,000 feet, the fact was, I needed oxygen. Peter Pan was going to have to grow up, and I was petrified.

I'd never been a father before, but I had a pretty good idea of what the job description was, and the notion of having to care for a child of our own created massive doubts. Could I pull it off, being so accustomed to an emotional 'duck and weave' lifestyle? Confronted with the reality that my life would change forever, I went into tailspins of self-doubt and opened a Pandora's box of petrifying fears. I'd just started a new business, I had no steady prospects or income to speak of, and at the time Bridget was the 'breadwinner' with her job. When Bridget had a baby, all that would have to alter. My headspace got scary, and I started to seriously think about running.

The following morning, I saw Bridget standing in the doorway, modeling her not-yet-showing belly to the mirror, and I knew then it was all going to be fine. Bridget was glowing and happy. I hunkered down to start making a plan. For years afterwards, when things seemed impossible, or impassable obstacles presented themselves, I simply recalled that image of my wife in the doorway of our tiny Charleston cottage, and I could muster the strength to push ahead. Bridget led by unfaltering example, all I needed to do was follow.

Playing with Cody, even before he was born

One of our childhood squat-in-front-of-the-TV programs was *Spanky and Our Gang*. It was always televised in black-and-white, and always anchored in the notion that kids of a feather stick together. We Sheehan kids never had to argue over what channel we wanted when the program aired; it was unanimous among us.

In one of the segments, one of the ragamuffin kids rubbed the belly of his black buddy, 'Buckwheat', suspected of possessing magical powers, while repeatedly making a summer's day wish: 'I wish Cotton was a watermelon!', 'I wish Cotton was a watermelon!' During the segment, the belly-rubber got his wish. (You'd never-ever get away with it nowadays: two black actors, one nicknamed 'Buckwheat' the other 'Cotton'?!) In 1960, I recall drinking water in a Greyhound bus terminal in Atlanta, Georgia with a sign over it reading 'Blacks Only'. When I loudly asked our mother what it meant, she quickly shuffled us kids back onto the Florida-bound bus.

When Bridget began to 'show', I'd tenderly rub her watermelon tummy, soothingly saying happy-time things to the baby growing in her belly. I never-once, asked for a 'watermelon'. If Bridget thought this was daft behavior she never said so, and willingly let me have my way with her abdomen. Bridget, in turn, played her favorite music for our belly-bound baby, and for all our future offspring, while she made a nest for each of them inside her.

Bridget flatly refused any alcohol at all during her pregnancies and ate healthful stuff. Not even an aspirin went into her if she could help it. Meanwhile, we occupied

a world where you needed to have a drink at hand to be social; Bridget asking for water or juice, in some settings, was considered a slap in the well-heeled ass of our southern hosts. Like a rock, Bridget stood tight and smiled through her champagne flute filled with juice. I tried hard to make up for her antisocial behavior by drinking both our shares of grog! Bridget was a fabulous 'designated driver'. I diligently cut back on nothing, and maintained my weight, and my social drinking, throughout all three of 'our' pregnancies.

Reality hurts!

When I stepped away from the architectural offices of Goff Associates to launch Publicity Plus, I signed Bridget and myself up for a family policy with Blue Cross/Blue Shield. I selected the top coverage for a whopping \$300 a month and made certain our coverage included maternity benefits. We were planning ahead.

Bridget's birthing suite was very like a Hilton hotel room: until you noted all the medical gizmos and clinical apparatus hidden behind aesthetically pleasing louvered doors. Tucked in there was all manner of equipment, just waiting for game time. Our coverage paid for two days of this bliss. After that we were on our own for extensions. In the USA, you get tossed out of hospital two days after giving birth, otherwise you pay extra. Lots extra.

A nurse handed me a special set of clipping scissors, and I cut the umbilical cord that connected our son to his mother. I did it though a faceful of tears.

Cody's cat crawls into his cradle

Cody was a smiling, happy baby when we brought him home from the hospital to our cottage in Henrietta Lane, Charleston. Bridget's cat, Gurdy, who'd previously enjoyed full run of the domain, instantly adopted Cody as her own. She would occupy the foot of Cody's crib, which amazed me, as Cody's turds truly ponged, the vapors seemingly able to penetrate leaden walls – an aroma that should have sent up red flags, or rung alarm bells. Poos from un-enzymed CF kids are horrifically ripe. They pong.

We worried Gurdy-cat might accidentally smother Cody, so we made alterations to his crib to safely accommodate her. I was already on the way to becoming a neurotic father, and we planted the crib at our bedside. No need for the high-tech baby monitor. Before Cody was born the cat always took up her place at the foot of our bed on Bridget's side and I would sometimes kick it in my sleep.

Something's just not right

Bridget knew instinctively that something was just not right about our son. She ignored well-intentioned advice about letting Cody cry at night and religiously fed our baby whenever he called out. Bridget extracted breast milk by way of a battery-powered gizmo she attached to her boobs, and when she was too tired to do a 2, 4 and 6 am feeding, I happily fed Cody his bottle from our bed as Gurdy kept vigil, watching me like a schoolmarm, making sure I got the procedure correct.

Our conspiracy to feed Cody was covert, as the experts

kept suggesting that giving in to feeding requests at all hours was setting the stage for a spoiled child. Bridget's instincts have always been good, and I was happy to go along. I have no stomach for the sound of any child crying.

Our baby doctor repeatedly reminded Bridget to just relax; this was, after all, our first child. And 'doctor knows best'.

Bridget insisted that there was something more sinister going on inside of our son, and with dogged determination kept returning to doctors' waiting rooms. When I could, I'd go along to heist a dog-eared copy of the *Reader's Digest*. I've been stealing them from doctors' and dentists' reception rooms since the seventh grade. On the last go-around, the paediatrician said they'd administer a 'salt test' for cystic fibrosis, but she was quite sure this was not what was ailing our son. Looking back, I think she was also already convinced it was a simple case of parental anxiety around a first baby which inspired our many treks to see doctors. The medical community was far too professional and polite to suggest Bridget was being neurotic.

The call that changed it all

I took the call from the doctor's receptionist, asking us to please come to the office after visiting hours, and preferably without Cody. When we arrived after five with our son, the receptionist seemed downright displeased. She'd now have to stay after hours and monitor Cody while we spoke to the duo of doctors in their chambers. I knew something was up. Bridget reluctantly eased over our six-month-old son to the

lass at the front desk. The reception area was populated with small, child-sized tables and chairs, and the walls were adorned with smiling turtles and penguins dancing. The floor featured open toy boxes containing hundreds of small, attractively colored plastic pieces that could easily lodge in Cody's throat. I notice things like this. I'm a natural worry wart.

What the doctors confirmed was that, despite their best guesses and earlier notions, our son had tested positive for cystic fibrosis. They tested twice to be certain. The two female practitioners took turns speaking calmly, suggesting that great strides were being made in the treatment of CF. They cautioned us to *not* go looking for answers in the library archives. The information we'd find there was not only out of date, but dreadfully alarming.

Bridget and I, our arms folded in our laps, sat quietly as the doctors spoke. And I could see the teardrops rolling slowly down the cheek of my wonderful wife. I was numb and didn't fully understand what this diagnosis meant down the track. I think Bridget had an unspoken premonition all along. The other thing I recall with great clarity about that day was the weather. It was 98 degrees (37 Centigrade), with almost the same humidity. Our Chevy Nova car had no air conditioning, and I recall being soaked. Looking over at Bridget, I watched a mother hugging her child tightly, all the way home to Henrietta Street.

Cody slept, nested between us that evening instead of in his bedside crib, and we again had Gurdy-cat at our feet, watching over her child. It was the first time in six months we all slept in the same bedding.

I ignored the doctors' suggestion of not doing the homework and, instead of going to the office, I pedaled Bridget's flamingo-pink bike to the Charleston Public Library and peered through the windows, waiting for the doors to open. What I discovered in the literature was devastating ... my beautiful Bridget and I had given our Cody a genetic death sentence; he was not expected to live long enough to attend elementary school. Unknowingly we'd gifted our boy with the dreaded double Delta F508 mutation of cystic fibrosis, the very worst marriage of mutant genes.

Help put us and cystic fibrosis out of business!

On the day that Cody was born, the average lifespan for a CF kid was six to eight years of age, but breakthroughs in the treatment of cystic fibrosis seemed to be cropping up weekly and I was convinced a cure for our Cody was only days away. With the uncovering of the gene that caused CF, came an entire new wave of activities and medications that could improve our Cody's odds.

Bridget and I were keen to do something, so with the help of Bridget's brother Michael in Hong Kong, we imported three, 40-foot containers of furniture and ceramics from the far east, and opened up 7000 feet of retail space along King Street in Charleston, with the sole purpose of raising funds and awareness for CF. We'd never heard of it till Cody was diagnosed with it!

For us, and the baker's dozen college kids who chipped in, we felt every customer held the potential to help find a

cure. Some folks spent only a few dollars, while others spent thousands. Even browsers got a flier about CF to take away when they went.

I threw money at a heartfelt TV commercial, solicited the support of the mayor's office, Kiwanis and Rotary clubs, and my buddies at the Hibernian Society passed the bucket around. The newspaper, radio and TV people were all pleasantly in our top pocket.

The night before we opened, we filled galvanized buckets with beer and champagne, and invited the top shelf of South Carolina society to take a sneak peek; black tie, or blue jeans, we took orders on the spot, and promised to deliver the next day. That evening, the till closed at \$25,000, with some folks just making a 'small contribution' to the effort, without taking a single thing home but our appreciation. Cody was there, never leaving his perch in Bridget's arms. He was all smiles, and when his Uncle Jim poked his belly, he laughingly poked back.

At eight o'clock on the morning we opened (at 9!), there was a line of 25 people clamoring on the King Street footpath to save 'up to 75 per cent off our products' if they were willing to learn about finding a CF cure. Nobody left our shop without a CF flier.

I've never worked harder, or longer hours on my feet in my entire life. We were open six days a week, from early till late, made free deliveries in exchange for a CF contribution and, in the end, moved over US\$250,000 worth of support selling Asian items. Support for CF research and patient services came not only from our customers, but also from wellwishers. We had people ask us repeatedly if were

considering staying in the furniture business full-time and offers to 'sell the franchise' as a money-making proposition. In the end, we kept to our schedule, sold every single bit of inventory we had, and hung a massive THANK YOU! sign in the window when we left.

We had help everywhere we turned. A generous property manager, Colleen, gave us the space for next to nothing, and we in turn said we'd find her a long-term tenant when we left. The Port of Charleston under Bernard Groseclose (our son Dylan Thomas's godfather!) permitted our containers entry without handling fees, the lovable mayor Joe Riley, lieutenant governor, chief of police and other top-shelf locals openly supported our full-frontal campaign for cystic fibrosis, and the Bank of Charleston's Carmel Dodds set up our credit card acceptance and banking 'on the house'. Every member of the Carmody and Griffith family pitched in to help. Both the Rotary and Kiwanis clubs drove clients through our doorway daily and offered to roll up their sleeves as well to help.

Sharing our dream with our community, we discovered we had heaps and heaps of help. I discovered that Bridget and I were not alone in this campaign to see our son, and others with CF, do well. All those generous shoulders to lean into helped me, come out from under the covers.