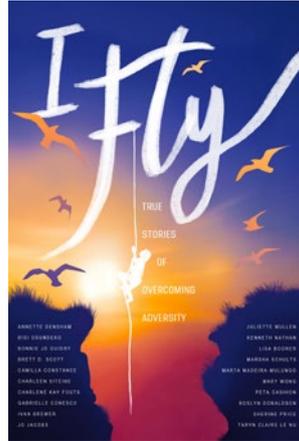


Excerpt  
from



True  
stories of  
overcoming  
adversity

# Why me, why not me?

## Bisi Osundeko



“Please wake up, my waters just popped,” I say with a sense of urgency.

My husband Mayor rolls over and rubs his eyes. “Water?” “Water?” “Which water?” he asks.

“Look, dear, this is serious,” I say, and emphasise pointing to my protruded belly which is fast deflating.

He sees the soaking wet towel. “Oh my God, what happened, Bisi?” he asks.

“I can’t feel the baby move anymore so we need to ring an ambulance straight away.”

“Bisi, Bisi. Why is this happening? Are you in pain? You seem calm!!” Mayor screams with his hands on his head.

He then starts speaking in tongues... several languages... but I am concerned about the fact that time is already ticking and the towel I am holding tightly to my body is already getting badly soaked as well.

“Honey, please be strong and ring an ambulance right now,” I plead.

I have already started searching for information on urine leakage in pregnancy online and I think that what I am experiencing is normal.

The team of paramedics arrive with the expectation that I am due to deliver right at home.

“Mrs Osundeko, can you feel any movements in your belly?” the paramedic inquires, holding me with the expectation that I am going to collapse at any minute.

“Actually, I’m not really in pain... this whole thing feels surreal,” I reply.

“Bisi, can you feel Joseph moving?” Mayor asks.

“Erm, I can’t feel any movement or maybe our baby is still moving but I can’t tell,” I say.

“We have come prepared to help you deliver your baby right here at home. How regular are your contractions?” the second paramedic asks.

“No... In fact... God forbid. I will not deliver my own baby prematurely!” I scream while holding on to my deflated belly.

“This baby will make it to term. Please don’t treat me like a sick woman. My legs are working, and I can walk to the ambulance,” I plead, moving around as if trying to dramatise how strong I am to the paramedics.

“Bisi, we really don’t have any time to waste,” Mayor says, and then turns to the ambulance crew and says, “Thank you so much for coming so quickly. Please, how fast can you get my dear wife to the City hospital?”

In the ambulance, reality starts to hit me. I know the hospital well, and I am already familiar with the neonatal unit.

But I’m not ready to do this again. I really expected my current pregnancy experience to be completely different from my first.

“I am so scared,” I say out loud, to nobody in particular.

They rush me into a delivery room and one of the doctors comes over to examine me.

“Sadly, your amniotic fluid which ought to be a source of support for your baby, has completely leaked when your waters popped at home,” the doctor explains while holding a stethoscope to my belly.

“I understand that my colleague has already enlightened you about premature labour and I also understand that you are not new to the neonatal unit,” he adds, with a tone of comfort.

“Is there anything you can do to help?” Mayor says, stammering.

“Well, we can give an injection that will delay labour but considering that all your waters have gone, we are not sure about the results,” the doctor says.

“Oh Lord, please help us,” I whisper.

This is even more painful than my first experience with Joy.

A couple of days after, I am still in pain and sing all the time in my native Yoruba language. The other pregnant ladies on the ward look so startled and I forget they have no idea what I am saying. It’s been 12 years since I left Nigeria but the words come so naturally. I start looking at the clock, and the pain starts increasing. At this point, it isn’t just my belly that is aching badly, but my head, my entire body.

Fear grips me.

I fear that my life is ebbing away. My body is trembling, and I throw my hands on my belly as if I am pleading with my body to hold onto my precious baby. I am dashing through the room erratically as if in a dance as I continue to sing Yoruba gospel songs.

Suddenly, I feel as though my legs can’t support my body. I am staggering and losing my balance.

I gather all the strength I can.

“Please help me. I need a nurse. Please help,” I say to whoever is passing through the ward.

One of the nurses suggests they should get the foetal heart monitor to check if the baby is still fine.

Lo and behold, as soon as they check, commotion starts in the maternity ward. Every medic within the maternity ward runs towards me. Everyone starts running helter skelter. Nurses, doctors, serious looking people in scrubs, suddenly come to my rescue.

“Her baby seems to be in serious trouble,” one male doctor says as they carry me into a bed.

“Bisi, we are taking you to the theatre straightway for an emergency caesarean operation. Your baby must be out right now,” a senior doctor says with a lot of panic in his baritone voice.

“I’m afraid we won’t wait for your husband to get here because this is about saving your own life as well,” he adds.

I pray in silence. God, you let me down, I don’t want to go back to the NICU the second time, please just take me home.

Lord, I'm young and I don't have enough strength to manage another disabled child.

At this point, it seems my baby has been delivered within slip seconds because it is such a quickie caesarean.

"We finally found his heartbeat," one of the surgeons says, rejoicing.

I can hear all the conversation in the theatre but am way too sedated to fully understand what everyone present is saying.

I am drifting in and out of consciousness.

The environment in the theatre feels very serene, yet it feels as if I am in a bit of a tussle with someone. I don't want to wake up because I feel as if I am enveloped within so much uncertainty.

Over a long distance, I hear my name.

"Bisi, Bisi, please wake up," Mayor is crying. "I love you, please come back, my dear. The doctors said that the sedation ought to have left your system by now," he says.

I open my eyes.

"She's finally awake, she's awake," Mayor says, his eyes wet with tears. "I'm so happy to see her eyes open."

For a minute, I can't understand why Mayor is so overjoyed.

I attempt to touch my pregnant belly, but my hands can't move.

It then dawns on me that I am no longer pregnant. As if in a dash, I suddenly regain my memory.

"What happened to our son?"

"What does our son look like?"

"When did Mayor get to the theatre?"

"Who is looking after Joy?"

I ask Mayor multiple questions, one immediately after another, without waiting for him to answer the previous one.

The excitement suddenly drains from Mayor's face.

"Don't worry, they are looking after our baby," Mayor answers, as if trying to censor my questions. "For now, your own wellbeing is all that matters to me," he adds.

The suspense is huge; I can't understand the mood in the theatre.

"Relax for now please. We will take you to the neonatal intensive care unit (NICU) to see your son," a female doctor says as she walks towards where I am laying.

Mayor looks at me and we both gaze at each other.

This is our second baby and I remember that we desired our baby boy to complete our family.

As I am wheeled towards the NICU, the familiar environment starts playing out to me. I feel numb.

I want to cry but my tear ducts are dry.

Why am I walking this same path to the NICU again?

A nurse then points towards a lone incubator.

"That's your baby boy, Mrs Osundeko. Will you like to touch him?" she asks.

I look at her without saying a word and then look at Mayor.

"Your baby is too fragile at this moment to be carried but we can open a side of his incubator for you to touch him," she says in a reassuring voice.

I hold onto Mayor's hands tightly and we both move towards Joseph in silence.

He is so tiny, yet he is slowly moving within the glassy incubator. Mayor and I stare at Joseph for hours without knowing exactly what to say to each other.

Joseph's situation looks a lot more complex than Joy's did at the time.

This is the beginning of our second experience in the NICU.

During our time there, Mayor and I always pray with bereaved families even though it certainly wasn't our job to do so. Our empathy for others grows during this period and I discover that I am always moved by the plight of other families of sick children. Comforting other parents unconsciously brings me comfort and I start to discover my purpose because I derive fulfilment from helping others.

There was a couple that I can't ever forget; they'd lost their twin babies. We see them crying along the corridors. No questions asked, we just go over to hug them. Nobody refuses a hug at such trying times. We had formed new friendships within the walls of the hospital because it became our new home during those terrifying months.

Joseph is poorly and doctors often remind us that his chances of survival are slim.

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I thought back to the last time we were in the NICU – when our first child, Joy, was born.

On the same day she was born, as soon as I left the labour suite, a team of doctors had called Mayor and I into a room for a meeting.

“We are sorry to let you know that your baby has Down syndrome,” one of the doctors had said. Standing beside him, the others were nodding in the affirmative.

“It is impossible for my beautiful baby to have down syndrome or Down syndrome, whatever you call the syndrome,” I argued.

“Our baby looked perfect to us and she was already smacking her lips, showing readiness to breastfeed,” Mayor said.

“Are you making a mistake?” I asked.

“Did you notice that a midwife looked at your baby and she left the delivery room to call one of the doctors?” said the same female doctor with a tear in her eyes. There was sadness written all over her face.

This isn't the sort of welcome to the world I imagined for my beautiful baby whose presence was all I was waiting for to soothe my aching heart after losing my mum a month before my due date.

I continued to shake my head in disbelief while I was taking a look at each of the doctors, one by one. A part of me wanted to question their medical qualifications and the credibility of what they were collectively saying.

“Are you sure that my baby has Down syndrome?” I asked.

One of the doctors who rarely said anything then started to explain, “We actually have a robust method of identifying babies who are born with this chromosomal condition.”

“By the time we took Joy away from you to the neonatal unit, we examined her eyes, creases in her palm, toes and other facial features and it all pointed towards this same syndrome,” another doctor said, this time with a louder voice as if trying to reassure Mayor and I as regards the accuracy of their findings.

One of the doctors tapped me as if trying to check that I was alright.

“We then sent a sample of your baby's blood to the laboratory for confirmatory tests and this test also confirmed our diagnosis.”

“No, no, no, this can’t be true! Jesus, Saviour, please help Joy, help us!” I screamed with tears running down my face.

I clung to my chest. I felt violated. I felt surprised that while Mayor and I were put into another room after we left the labour suite, they were busy testing my precious baby as if she was a specimen.

A flurry of thoughts filtered my mind.

“We understand that you did not expect this news,” the doctor announced, as if trying to wake Mayor and I up from our trance-like gazing, crying, and praying.

“So, where is my baby?” I cried.

“She is currently in the neonatal intensive unit for sick babies, even though she was born four days overdue. Her lungs are not working the ways they ought to, so she is under a head box as well receiving oxygen,” the doctor explained.

“What is all this?” I asked as if I had just been robbed of a precious possession.

“One of our nurses is ready to take you and your husband to the NICU to see Joy,” one of the medics replied. “Also, please don’t forget that a representative of the Down syndrome association is also coming to talk to you and she’s coming over with some literature.”

I started crying loudly and the doctors looked at me as if they didn’t expect me to still be crying after all the wailing.

“We don’t want to be forced into this club of special needs parents or any association. We have no experience of parenting a special child, please,” cried Mayor.

However, the doctors were already on their way out of the room that we were in. I looked around and started to worry about my daughter’s future.

Mayor and I held each other as I was led into the NICU. It felt as if we were walking into uncertainties. We were so afraid. We had a million and one questions.

Joy was a big baby, considering that most of the babies in the NICU were premature. We really felt out of place. As the weeks went by in the hospital, I started attempting to breastfeed Joy but her breathing problems meant that she had to be tube-fed.

After some weeks in the hospital, Joy was finally discharged to go home. All the excitement that comes with having a new baby had subsided and we simply felt exhausted.

Being strong was the only option Mayor and I had.

During our time in the hospital with Joy, one of the nurses enlightened me about skin to skin care for babies and I was gifted a kangaroo care top which helped to facilitate bonding with Joy.

Unknown to me, that discussion was sowing a seed into my entrepreneurial future. Working or running a business was the least on my mind at the time though. I had no sleep. I was very afraid. Within such a short space of time, my weight plummeted though my eating was poor.

Prior to having Joy, I had set out the perfect future where I would simply let my mum help babysit Joy while I had my sights set on some top environmental firms in the Midlands that I was aiming to apply to for jobs.

I started to feel inadequate. I felt that if I was unable to nurture a perfect baby within my own womb, then I had failed completely. All the amazing academic achievements, scholarships and awards didn't matter to me anymore because based on my cultural Nigerian background, children were viewed as major achievements too.

Sleep deprivation made me feel like a zombie. I was constantly forgetting the days of the week or what time of the year we were in so I really couldn't imagine myself attempting a structured work system.

The perfect future to me was one where I was gainfully employed with a great company. Without a doubt, I started questioning my decision to have my first baby whilst I was still in the university for my Master's degree.

Though Joy was planned, her disability was not planned. Unknown to Mayor and me, that was only the beginning.

Joy later had tons of diagnoses added to her main diagnosis. Apparently, some of the conditions like hearing and visual impairment were linked to her trisomy 21 (T21) diagnosis also known as Down syndrome. At that time, it felt as if the doctors were saying that something was wrong with every single part of her body.

Whenever the phone rang, I would wonder what the next diagnosis was going to be.

We were told to expect that Joy was going to have an open-heart surgery to repair the hole in her heart.

Yet during that time Joy was home, in the midst of the medically induced chaos, I slowly started to bond with Joy properly. I realised that she was first of all, *my baby*; before all the diagnosis happened. Mayor had to go back to work because there was no other way our family was going to be able to survive financially if both of us didn't work.

With Mayor's encouragement, I slowly started brainstorming about businesses I could run from home. The options were limited because then in 2007, I didn't know anything about website construction or social media

marketing, so I started from scratch. I looked into childminding, online trading, and weekend markets.

I also experienced so much kindness from Dr Liz Marder. She often visited our home and would come upstairs into my bedroom to console me, when I was crying due to Joy's feeding problems.

Dr Liz later invited me to a support group. Something big shifted in my mind the very day I took Joy to the social event, a support group for families who have children with Down syndrome in our city.

The event was like a carnival. There were kids running around. Little kids, big kids. All these children have Down syndrome, yet they were so diverse.

Kids in wheelchairs and lots of kids without wheelchairs.

I went back home feeling as though something significant had happened to my mindset. I didn't feel alone in this new special needs parenting terrain anymore. This was the start of my love for support groups for parents of disabled children. I started looking forward to creating happy memories with my precious baby Joy.

I discovered that there were tons of other families with children like my daughter.

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It was two years after Joy's birth that her brother was born. After lots of months in the hospital, Joseph was discharged home. Although Mayor and I boasted to the doctors that we were keen to use our parenting experience for Joseph, we were quite scared. We had become used to the nurses and doctors being around, and now we'd be on our own.

Both Joy and Joseph were on oxygen at the time, so our home was like an extension of the hospital; only that this time, Mayor and I were the doctors. Joseph was also sent home with a tube that was inserted through his nostril into his stomach for his feeding. The feeding tube was like a little upgrade from the jejunal tube that was used in the hospital because his internal organs were not digesting food.

Around that time, when I was bonding with Joy and Joseph at home, I was struggling with the piece of clothing I'd been gifted in the hospital.

I need a sling which will allow me to be hands free.

Looking back, this was my eureka moment. I researched the baby sling options available in the market, but nothing appeared to meet my needs.

I drew inspiration from my African background and the traditional way I had been taught to nurture and carry babies on my back.

I brainstormed options, and with Mayor's support, I bought a sewing machine.

My business, *Joy and Joe Baby*, was born right there at home within my conservatory in the middle of my super chaotic life, childminding business, and special needs parenting.

The feedback I received from some of my early customers really opened my eyes to the fact that I was a people's person. I derive happiness from seeing others happy and fulfilled.

Around that period, I also started to experience isolation, mainly because working from home meant that sometimes my only face to face interaction in an entire day was with my children and husband. I saw a leaflet from the community association where they urged residents to participate in the community meetings.

This was the start of my community activism. I started attending these community events with a view to combating the sense of isolation I felt, and I met people who lived around me.

During that time at the community association, I saw they had no website, so I volunteered to help them design and create their website. I used the knowledge I gained from creating my own new business website.

A few miles from where we lived, I also found out that our local children's centre had a lot of group or play activities for children but there was nothing for disabled children and their families. After a discussion with a staff of the centre, I then started by sitting in the meeting room on my own. Then the following week, another parent of a disabled child came, and I slowly built the special needs support group from there.

This was like a whole new world to me. I began to feel a lot more fulfilled from the inside and my happiness radiated to the outside. I felt as though my life had a new meaning. I was so happy that I was able to contribute something positive to the lives of other families in addition to discovering my calling in life.

Through this support group, my understanding of our ability to thrive in the midst of challenges gave my life a whole new meaning.

I now look forward to every single day as a chance to positively impact the world around me. Though this was a corner in my city at the time, I felt as though I was touching the lives of millions.

The experience that I've had so far with my own children proved to be very useful when it comes to counselling the parents who came to me for advice. During the time that I was overwhelmed with Joy's many diagnoses, I didn't realise that all the experience was going to be useful for other families in the future.

I enjoy talking to people, listening to them talk about their special needs and entrepreneurial challenges, and offering my expertise and experience as a way of encouraging them. Through that, I organised a festive party for all the disabled children in my community and it was a huge success.

Over time, Joseph came off the feeding tube and started feeding orally.

Joy started nursery school and she was thriving beautifully.

All these in spite of their disabilities that I was initially so scared of.

My marriage grew from strength to strength.

My business continued to grow from strength to strength.

My self-esteem and confidence continued to grow from strength to strength, too.

I have gone on from a person who merely survived each day to a fulfilled person who has gained a superb level of clarity as regards her direction and purpose in life.

I have gone on to become a person who other parents saw as a treasure of knowledge because I unashamedly owned my challenges and I'm always more than willing to offer my entrepreneurial and emotional support to special needs families where needed.

My children have gifted me in ways they will never know, and I am truly grateful.



# Bisi Osundeko

## **Entrepreneur, Public speaker, Property Investor, Life Coach and Politician**

I have a passion for raising the next generation of business leaders from parents/carers of disabled children. Having navigated my entrepreneurial journey for over a decade as a parent to two little ones who were born with complex disabilities, I have a first-hand experience of the sort of challenges that this section of our entrepreneurial community face.

Outside business, special needs parenting can be very isolating, so I have set up a closed Facebook group (Joy and Joe SEN parenting support group) where parents of children with special needs can be empowered to start their own business whilst we also support each other emotionally. I look forward to welcoming you into our community.

In 2012, I won the prestigious mumsclub award as one of the top 100 business mums in the UK. In 2015, my business won the prestigious venture further award by the University of Manchester business school. In 2017, I won the Talk of Manchester Business Award and Best Female Entrepreneur in 2017. I'm also currently a Councillor in St. Helens.

A graduate of the University of Nottingham and scholar. I am the recipient of the prestigious DFID/Commonwealth scholarship for postgraduate studies. An OFSTED registered Early years expert and governor in two special needs primary schools in the United Kingdom.

E: [bisi@joyandjoebaby.co.uk](mailto:bisi@joyandjoebaby.co.uk)  
W: [www.bisiosundeko.co.uk](http://www.bisiosundeko.co.uk)  
F: @BisiOsundeko  
I: @joyandjoefamily