



# *Taylor's Journey*

*A Mother's Story*

*Jennifer Johnston*

This edition first published for Jennifer Johnston in 2009 by

Memoirs Foundation Inc. (Australia)

2 Burwood Highway, Burwood East Victoria 3151

03 9888 9588

[www.memoirsfoundation.org.au](http://www.memoirsfoundation.org.au)

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National Library of Australia Cataloguing in  
Publication Data

ISBN No 978-0-9805730-2-2

Typeset in 13pt Adobe Garamond by  
Synergy Publishing

Publisher: Arnold Bonnet

Project Coordinator: Deborah Longden

Editing: Lynne Bennett

Design and Layout: Sam Trask

Art Director: Mark Bonnet

Production: Wendy Wright

Printed in Australia

The opinions expressed by the author are not necessarily those of the publisher or editor.

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“Life never guarantees you an easy path to follow  
but with courage, strength and determination you  
will walk down the right road to happiness and success”



## Dedication

This is the true story of my youngest child's journey from a life of silence to the wonderful world of sound. Taylor's journey began from the time she entered this world. She was born profoundly deaf in both ears and suffering from a bowel condition called Hirschsprung's disease. She showed unbelievable strength and courage to overcome these hurdles and a steely determination to beat all the odds against her to become a very bright, talkative and happy young girl today. I would like to share her story with you.

This story is dedicated to my three children Lisa, Matthew and Taylor, and my husband Tony, who have supported me in completing this inspirational story of unconditional love during a time of anguish, uncertainty and the unknown. The support each of you have shown has made Taylor's Journey a very emotional, but rewarding one to travel.

Thank you to all of my family and friends, to the staff at Australian Hearing, the brilliant surgeons and staff of the Sydney Children's Cochlear Implant Centre and everyone at the Shepherd Centre for the tremendous support and encouragement you have given us in assisting me to teach Taylor to listen and understand language. Without your assistance and encouragement Taylor would not be where she is today. You have made such a difference to her quality of life. Thank you everyone.



## Chapter 1

### *A Mother's Instinct*

I was forty-one when I fell pregnant with Taylor. I had two older children from a previous relationship; my eldest daughter, Lisa, who was twenty three, and my son, Matthew, who was nineteen. My children were grown and planning their own futures. I had a secure job working in a public service position and my husband Tony was working with his family's business.

Before Tony and I decided to get married we talked about having children. I had a tubal ligation approximately seven years before because I hadn't planned on increasing my family and I needed to know if I could get a reversal. At first, my gynaecologist tried to talk me out of it, but as Tony had no children of his own, I was determined to at least try for him. I had to go through various tests and counselling sessions before they would even consider doing the reversal, and Tony also had to undertake tests. After we were given the go-ahead, I booked in for the reversal operation in January of 1998. Everything went really well and I was advised to

take things easy and wait until I was fully recovered from the surgery before trying to get pregnant.

Tony and I married in May 1998, and at the wedding, I told him that we were expecting in front of all the guests. He was over the moon and so were my children and everyone else present. His parents couldn't believe it. I was only about four to six weeks pregnant and felt great, but a few days into the honeymoon I started bleeding and suffered a lot of pain. I was losing the baby. I had a miscarriage the day before we were due to come home. We had been so happy and to lose the baby on our honeymoon was devastating. Tony was so upset that I could almost feel his pain physically.

I visited my doctor for a thorough check up the day after we arrived home. He told me that miscarriages can happen for no apparent reason; I had done nothing to cause this and should not blame myself.

“Just wait a bit longer,” he said. “Let your body heal from this before you rush into trying to get pregnant again.”

He was very comforting and reassuring. Maybe it was too soon after my operation; I don't know why it happened but both Tony and I listened to his advice and waited. After a few months, I approached a naturopath for some advice and within a month, I was pregnant again. It had taken us eight months and when I looked at the calendar it was exactly twelve months to the day of my operation. We waited a bit longer this time before we told everyone that we were expecting again. Everyone was very happy for us. Tony's parents, Noel and Leonie, were extremely happy as this was going to be their first grandchild and, of course, Tony's first child.

I couldn't believe that after such a long time I was having another baby. All our friends and family said to me, “Oh,

you'll be a natural; you've done this before. You're older and wiser now, everything will be fine."

My pregnancy was nothing out of the ordinary; a couple of days of morning sickness and that was it. I kept working because I was feeling great and all the tests I had showed no abnormalities or any unforeseen problems with the baby. We set up the nursery and had everything prepared for the safe arrival of our beautiful baby girl.

My due date came and went without a hint of an impending birth. I visited my local hospital for another check-up four days past my due date and was told that I was going to have to be induced due to high blood pressure and fluid retention. The nursing staff advised me that this was a common thing with pregnancies and not to worry about anything. This was it! We were having our baby today.

Tony and Lisa were with me during the labour and birth and they were such a great support to me throughout it all, I couldn't have done it without them. After a few hours, our beautiful baby girl arrived. Taylor Maree Johnston was born on the 8th October 1999 weighing 7lb 15oz. Tony was so proud to be a Dad for the very first time; he had a smile from ear to ear. Lisa had tears in her eyes; she had a little sister and was very proud of her. Noel and Leonie, who had been waiting anxiously in the waiting room, came in to see and hold their beautiful granddaughter. The midwife handed her to me for my very first cuddle. I looked into Taylor's eyes and had an overwhelming feeling of happiness and sadness at the same time.

What I saw can't be explained. She had this faraway look in her eyes and I believe she was trying to tell me that something was wrong. I know that sounds weird, but that's

the only explanation I could find for myself. At the time, I felt relief that she had arrived safely, but I also had a vague sense of unease.

Tony and Noel and Leonie were so excited about seeing Taylor that I didn't mention anything to them at the time. Lisa's partner, Mick, and Matt and his partner, Josie, came in to see her and they all had lots of cuddles. After they left, Leonie and I were checking Taylor over and noticed that her arms and legs had a lot of loose skin, as if she didn't have much fatty tissue beneath it. I guess you could say she looked malnourished, but when we mentioned our concerns to the midwives and nursing staff, they all said she was fine. I was taken to the maternity ward and after Tony, Noel and Leonie left, I raised my concerns with the staff about Taylor not having passed any meconium (first bowel movement) yet. I knew something was wrong but again, the nursing staff told me not to worry.

Taylor wasn't interested in feeding; only sleeping. The midwives said, "Let her sleep, she's had a big day you know, she'll wake when she's hungry." I was perplexed about her ability to sleep so soundly in the noisy maternity ward; nothing could wake her, nothing startled her at all. All the other babies were crying and keeping everyone awake, yet Taylor was oblivious. I didn't want to think that she may have a hearing problem; I was more worried about why she still hadn't had a proper bowel movement and why she wasn't interested in feeding from my breast.

I persisted in voicing my worries to the staff.

"Please check her," I asked, "because I'm getting quite worried about her."

But the midwives and nursing staff just said, "Babies do that sometimes, she's just tired and needs to rest."

I wasn't convinced. I knew that a baby had to feed and have a bowel motion. I had previously had two other children and I wasn't stupid. They just kept telling me to rest and relax.

"She'll feed when she's hungry," they said. "Maybe she's a bit constipated."

I was extremely worried on the second night. Taylor suddenly brought up green bile and immediately I took her to the midwife on duty. I told her that something was wrong with Taylor and I wanted a doctor to look at her, but she told me that it was nothing and advised me to stop causing a scene. Taylor was jaundiced, she said, and I should simply put her in the sun in the morning and someone would look at her tomorrow. The doctor came and listened to her tummy and said that her bowel sounds were normal and that she was slightly jaundiced. *This place is a joke*, I thought. *Why won't someone listen to me?* Taylor still wasn't feeding properly and I wanted to put her on a bottle to give her some fluids, but they just told me to keep trying with the breast. "It's better for her," was their constant mantra.

After three days Taylor was looking extremely jaundiced. The sun treatment wasn't working for her, but again, the staff said that she would be fine in a few days. It wasn't bad enough for me to worry so much, they said. They accused me of being a neurotic mother; I ought to just let her be. I discharged myself from the hospital and on the way out I said, "I know there is something wrong with her, and I'm going to find out what it is. I'm taking her to my own doctor for some answers."

I will never forget the comment made by a family friend who came to visit us in hospital the day after Taylor was born. She couldn't get over how perfect Taylor's ears were and how lucky she was. This friend had problems with her ears when she

was little. They used to stick out, but Taylor's were perfectly shaped and formed. In my mind I was thinking, yes they are, but I'm not sure if she can hear with them. They weren't performing hearing tests on newborns at the hospital at this time. Newborn hearing screening in Australia came out a couple of years later.

I will never forget the day Taylor came home either. Tony had gone into the house and I was taking her out of the baby seat when the back door of the house slammed shut so loudly that it scared me ... but Taylor wasn't startled at all. There was no wind that day and no reason for the door to slam shut, but it did, and it happened at the same time that I was looking at Taylor. It was then I knew that she couldn't hear. She was three days old. I didn't say anything to Tony at the time because I needed confirmation first and I was more concerned about her lack of interest in feeding and that she hadn't had a bowel movement. *Taylor looked very sick.*

We were so concerned about her not drinking from me that we decided to try her with a bottle. My sister, Margaret, who is a midwife and a great support to me, came over and tried to get her to drink. She took some milk, but was very sleepy so we put her in her cot to rest. Margaret told us not to worry and that the doctor would be able to help us soon.

That night, after Tony had gone to bed, I sat in the lounge crying uncontrollably, to the point where I was physically sick. Why did this have to happen to our little girl? What did I do wrong? Was it because of my age? Was it my fault? How am I going to tell Tony that I think Taylor is deaf? I tried not to think about it because I desperately needed to know what was wrong with her.

We took Taylor down to the doctor the next morning and I

explained my concerns to him. He took one look at her and was horrified that the nursing staff hadn't noticed that she was very ill. He sent us to the emergency department of the hospital and Taylor was immediately taken to the neo-natal unit and given antibiotics. Our baby was lying there with tubes down her throat and needles in her arms. They placed her on a drip to give her the fluids she so desperately needed because she was dangerously dehydrated. Numerous blood tests and other tests were taken, but I couldn't hold her or cuddle her and the pain I was feeling tore my heart apart. Tony couldn't bear to see his little girl like that. *This was not supposed to happen.* The hardest part was leaving her there when we went home. She was with strangers, without her mummy and daddy and that knowledge was unbearable for me.

Tony and I couldn't believe that Taylor had to suffer for three days because nursing staff hadn't listened to me. One of the midwives from the maternity ward who accused me of being neurotic, came into the neo-natal unit to look at another baby and was shocked to see Taylor lying there looking so sick. All I could say to her was, "Do you believe me now? I told you there was something wrong but you wouldn't listen."

A mother's instinct should never be ignored, but they did ignore me and our little girl suffered because of that. Taylor had suffered needlessly due to staff carelessness and lack of concern. Because her bowel wasn't working, her abdomen was distended and she was suffering from projectile vomiting. One of the doctors on call in the neo-natal unit was so concerned about her abdominal distension that he took an X-ray. He told me that it looked like Taylor had something wrong with her bowel and that she would be transferred to a hospital in Sydney where they could investigate it further, and also monitor her and try to get her to feed. Taylor was taken by

patient transport to the hospital. We had to travel in our own car; we couldn't go with her.

We got to the hospital and saw so many tiny babies in there who were sick and premature. It was a sight I will never forget. Taylor looked so big next to them. To the nursing staff, Taylor looked fairly healthy because she had been a full-term pregnancy and they were used to seeing premature babies all the time. I raised the fact that she had not had a proper bowel movement and that she wasn't feeding properly. They told us that they were going to concentrate on getting her to feed first before getting the doctor to have a look at her hospital notes in relation to her bowel.

Due to lack of parent accommodation, we weren't allowed to stay at the hospital. The staff advised us to go home and come back in the morning; they would keep us informed of her progress. "Go home and get some needed rest," they said. "Taylor's in good hands here, don't worry."

But that isn't easy to do; you can't help but worry. The next day Taylor projectile vomited again and the staff thought she might have reflux. They treated her for reflux and after a while she began to feed really well. I remember that both Tony and I thought, *Hey, maybe everything is going to be fine and that's all it was.*

The doctor checked her tummy and said that she had normal bowel sounds and that it was soft and she showed no sign of distension, but again, I questioned her.

"Why hasn't she had a bowel movement then?" I must have asked that question a hundred times and always got the same answer, "She's constipated."

They gave her a suppository and Taylor did eventually have

a small bowel motion, but it wasn't a normal motion. To me, all of her motions resembled rabbit pellets. As she was feeding, and her jaundice had gone, we were finally allowed to take her home.

Taylor was now two weeks old and it was going to be another three weeks before the real reason behind her condition would be revealed. They never did take any notice of what the doctor had told me at the other hospital about her bowel; they treated the whole situation as a simple case of reflux.

One week after her admission to the Sydney hospital, we brought Taylor home. The staff assured us that she was going to be fine now and told us to just enjoy our beautiful little girl. But as the days progressed, Taylor still didn't seem right to me. Even though she was feeding she wasn't thriving or growing at a normal rate. Friends commented at times with the words, "She's still so little," and "How come she hasn't grown much?" She was now one month old. Every day, I would say to Taylor, "Mummy will fix whatever is wrong, sweetheart, I promise. I'm so sorry that you have to go through all this." I just wished I knew what this was.

The doctors couldn't tell me anything other than that she was constipated. *But there had to be some other reason for her not toileting properly, there just had to be*, I thought. Why do they keep saying that she is constipated? By five weeks of age, Taylor's stomach was so distended that neither Leonie nor I could believe it. The left side of her abdomen had become hardened and swollen to the point that we thought it was going to burst. You could see all these lumps under her skin and the veins over her entire abdomen became very prominent. Later on, we found out that this was all caused by a build-up of faecal matter. Five weeks worth, to be exact.

After numerous attempts to get a medical person to listen to what I was saying, and going crazy in the meantime, Taylor's condition had deteriorated to the point that she was seriously ill. I took her straight to the emergency department and this time, they were going to listen. I demanded that something be done and I wanted it done immediately. They did a barium enema on her to see what was going on and that's when they discovered that Taylor had Hirschsprung's disease, which is a disease of the bowel. Taylor underwent surgery the next morning. She had a colostomy. She was five weeks old.

As I carried her into the theatre, I kissed her and said, "Mummy and Daddy love you very much and Poppy in heaven will keep you safe." My dad had passed away in 1996 and I missed him so much. He absolutely loved his grandchildren and I wished he was here to see Taylor. As I put her on the operating table I couldn't believe how small she looked. The nursing staff assured me that she was in good hands and that everything would be fine. Her surgeon was brilliant, they told us, but he didn't have a very good bedside manner. We didn't mind about that, as long as he took good care of Taylor, that was all that mattered to us. He had listened to us and knew exactly what needed to be done. Why hadn't the other doctors listened? Why did it take five weeks to find this out? Why did she have to suffer so much before they did anything?

The doctor who performed the surgery saved our little girl's life and we will be forever grateful to him. Taylor's bowel was so diseased that she could not pass any faeces through it. She would have to wait until she was eight months old before they could perform further corrective surgery. In the meantime, Taylor would have to wear a colostomy bag to collect faecal matter. He explained to us that Taylor had a small section of diseased bowel that wasn't contracting enough to make a bowel

movement possible. We could have lost her if this condition hadn't been unveiled. The disease had caused Taylor's infection and it was behind all her other problems too: the bilious vomiting, failure to pass meconium, poor feeding, jaundice, slow growth, sleepiness, lethargy, abdominal distension, projectile vomiting and the sole reason she was unable to have a bowel movement.

Hirschsprung's disease was something I had never heard of before and most of the medical people I spoke to said that it wasn't very common; about one in five thousand children. I now needed to find out as much information as I could and my sister Margaret was wonderful. She gathered a great deal of material for me to read so that I could get a better understanding of why the disease occurs, when it occurs, and what steps to take to ensure Taylor didn't suffer anymore.

I was stunned to find out that this disease develops before the child is born and begins when the nerve cells stop growing. In Taylor's case they had stopped growing when they reached the large intestine. This meant that as the nerve cells weren't present, no message was getting to the brain to tell the muscles to push the faeces through. There was nothing I could have done to prevent it happening and ultrasounds are unable to detect it, which explained why everything always appeared normal. I felt relief through the knowledge that at last we had a reason for Taylor's illness—and then I thought about how Taylor was going to cope with it all.

I needed to be the strong one who was here for her, and for Tony, who wasn't handling it too well. Our families, and especially my elder children were extremely supportive, and that made coping so much easier. Don't get me wrong here—it definitely wasn't easy. It was the hardest test I have ever been put through and an even harder one for Taylor.

When they performed the colostomy they made two holes on the outside of Taylor's body called stomas. They did this so that when it came to the second operation, the doctor would know how much diseased section had to be removed. The first stoma was for the faecal matter to pass through and the second stoma would be used to join the healthy sections together during the second operation, which would be done when Taylor was eight months old. Taylor needed to get healthier and stronger before this could happen. In the meantime, learning how to fit a bag was proving to be very difficult. We had a stoma nurse come out to the house to show us how to fit it, but because they had given Taylor two stomas, the bag was not going to work. It could not adhere to her abdomen because there wasn't enough room between the two stomas for it to stick.

Both the stoma nurse and I were at a loss as to what to do. How was the faecal matter going to be collected without the bag? The only thing I could think of was using breast pads. Taylor's bowel motions were loose and frequent and we needed something to absorb the matter. The pad would cover the stoma and Taylor would wear a nappy over it, which would prevent her clothes from ending up in a mess. I had to cover the whole area with lots of protective cream to prevent nappy rash, just as I would if Taylor's bowels were normal and this was the way for Taylor, at least for the next seven months.

It took its toll on the family and especially on me, because I was changing her every thirty minutes or so to prevent rashes around the stoma. It must have been uncomfortable for her and seeing your baby having to go through so much was, at times, a hard pill for me to swallow. Life sure had been cruel to her, although I know that there are never any guarantees in life. You just do the best you can with what you have and Taylor was doing the best she could with what she had been given. At least she was a happy child, which made all of this less stressful for me and everyone else around her.