

Jaime's Testimony

“Life isn't about waiting for the storm to pass, but learning to dance in the rain”

The Journey to where we are now is vast and great. When I look back on the years that we have walked through, I am always amazed at His faithfulness and goodness to us as a family. I was actively involved in all kinds of things as a child, from being part of the Surrey and Sussex champions gymnastic team, to dancing in recitals and competitions in different dance genres. I sang in musicals, did theatre productions and auditioned and performed in several child roles in professional theatre productions. I loved to play and write music and sing in my church in the worship team; I was an active young girl with dreams and aspirations to go on and do performing in some degree or another with dance and musical theatre at its core.

My faith was very important to me, growing up in a Christian home with my father travelling all over the place to evangelise in many areas of the country (before he became ill). My sisters and I were used to being asked to sing as a group at his meetings and he later authored a book. It was a childhood filled with dreams and aspirations as well as sadness and trials. My father was very ill from around my 14th birthday. He struggled with heart disease and strokes. It was challenging and money was very hard to come by as my mum tried to hold the family's finances together by taking on multiple jobs as my dad was unable to work. I led a dance and drama youth group at 14, having to move from our living room as it grew so quickly; a real passion burned in my heart for the arts.

My childhood went on to take a turn when I experienced years of physical and emotional bullying in my GCSE years, which stole my dreams, my confidence and led me to stop singing, dancing and performing. I was broken and unable to find myself.

I searched for acceptance in unfamiliar places and my first love, my Jesus, was lost as I strayed from God searching for who I was - my identity.

During my early to late teens I experienced strange and debilitating symptoms that no one could figure out, the doctors put it down to chronic fatigue and glandular fever and I pushed

through not knowing anything else, probably over-training my body, pushing it too hard with ballet and gymnastics.

My life during my teens was complicated, I was searching for acceptance and who I was, my identity buried with the bullying, gone were my dreams to perform and I couldn't find the confident child and teen that once was.

A turning point in my life was when the Lord poured out his forgiving and unfailing acceptance on me even in my broken places and he took a backslidden teen and changed my life in His arms again. More can be read about my teenage journey in the link below to the more in-depth story.

As my teenage years progressed I became more and more unwell and by the time I was 17 I had laid down my hopes and dreams to go to stage school and taken on a job in a Christian accountancy firm so it wasn't too much stress on my body, but my real desire for the arts had gone and I couldn't find it again.

I met and married at 18. Some may say 'Seriously?' but God knew what he was doing as about a year afterwards I fell seriously ill, was unable to function and my new husband became a full-time carer for me. Over the period of our marriage (now 19 years) he was to take and lose many jobs to fit in with my up-and-down health.

We had bought our first home together and it was my pride and joy, but when he gave his job to care for me the insurance would not cover the named illness and we had our home repossessed; it broke my heart.

We became dependent on welfare and then we were told the disease they thought I had was 'lupus' or a 'mixed connective tissue disease' and the plight to be sent to multiple specialists began. I was prodded and poked and tested and put under many investigations, as I was an 'interesting case'.

One thing they said for sure was I would not be the strongest person to carry children and they advised against it. They predicted I would have to spend a lot of time at the teaching hospital in London as a high risk and they were not confident I would carry long and it really was not worth it. The consultants said the condition would not kill me but I would be disabled for all my life and told me to get used to it.

My husband and I longed for children and we longed to have a family, so we loved and lost one. Then through sheer faith and trust we carried our first, we gave birth to our beautiful son and I experienced wild symptoms with my heart racing uncontrollably for hours after birth and at the time no one knew that this was the one symptom that could have led to a firm diagnosis.

I wasn't able to dance, and my singing had stopped apart from at home where I would write and play. I suffered anxiety and low times when my health was so bad I would cry myself to sleep because I couldn't do all the things that were in my heart. The courage and dream had died with the bullying, but even if I could heal and find Jai again, now my body would stop me from doing it. I was broken.

Over many years I dreamt of dancing again and performing, my husband and I helped in youth camps and led youth departments in our church, we attended bible school for a short time, cut short again by health. We rented many homes, for various reasons - landlords sold, increased rent or we had damp! It was certainly a journey as a young married couple.

Monies were super tough, living on welfare again - it was like living my childhood over.

My health grew slightly more stable and during that time my husband and I launched out and I started to teach a few children in the local area musical theatre and we put on outreaches in the local theatres.

We started a creative literacy business in schools in the local area, teaching history and English curriculum through the use of arts, drama and storytelling. It wasn't performing but was the arts in a small way. My confidence started to grow and although my health was still challenged we were living some.

I met a dear friend in the close that we had moved into that got me involved in a local operatic and dramatic society and surely but slowly over the years I started to be involved in the musicals and then landed leads. I was finding my confidence again, but my health was still challenged and limited energy outbursts led to peaks and troughs of being really poorly and then able.

My health was getting better and my husband was offered a full-time job for the first time in years, so we moved with my husband's work to Hertfordshire. We had money!

We had gone on to have two more children despite all the words of the doctors as my diagnosis fell within a mixed connective tissue disease and although the pregnancies were hard with the support I made it!

God was good, our marriage strong and I had some, although limited, energy. In our hearts, we had a dream for a long time to use the passion we both had in the arts and primary education system and our love from God began to realise our true destiny and purpose. We started Manna Academy once a week teaching children ages 4-18 to do dance, drama and musical theatre. We started to thrive and it started to blossom and grow. The classes were donation-based, it didn't bring income but oh what joy!

Then in 2009 I was suddenly hit with symptoms that were so disabling every time I stood or sat up my heart would race, I would feel breathless and faint and soon over periods of weeks and months I was totally housebound, Manna was laid down and once again my confidence left so quickly. This time I was sure I would never find the strength to live again.

I spiralled quite quickly through various degrees of anxiety and low times having had a dream reborn and confidence rebuilt to have it all taken in weeks, an academy we had worked so hard to build, just gone, I felt like dying and inside I did.

I became housebound for two years as my ballet shoes and Manna shirt hung in the bedroom, my husband was once again carrying me everywhere and I crawled like a dog to get around my house, anything upright and I would be really unwell. The doctors started the search again and after over 100 appointments all over the nation, a doctor nailed it. I had Ehlers-Danlos syndrome, POTS and autonomic dysfunction, mitral valve prolapse, spondylitis in my spine and scoliosis, gastric dysmotility and that was just the major diagnoses! However, that was not the end. Now with three children all with varying but similar health struggles it was said what they first thought in me was mixed connective tissue disease, now was not and was a genetic condition that they all most likely had, we were sent to GOSH and it was there it was confirmed.

The guilt and the condemnation I felt were intense, there I was, useless and dependent on my wonderful man, who was unable to work became the mother and father to our kids, but my beautiful babies had this thing too. We did not know to what degree but the guilt was intense.

It was in those dark long days of intense longing to even be able to get down the road in the car without throwing up or being so dizzy I would faint, or exhausted from putting on my socks that God began asking me to write musicals.

I almost scoffed at him, as much to say “Seriously – you want me to dream of all the things I can't do, I couldn't even get through act one and you want me to write my dreams on paper and not be able to do them?”

I was angry and at the same time, I felt a tug that this was destiny and important. So I started writing. Then He asked me to “Put on your shoes, yes, your ballet shoes and wear them as slippers all around the house, as a testimony you will not only stand again but will dance.”

That was a push way too far for me and in anger, I sobbed into my pillow.

Months on and I was wearing those worn comfy shoes as I crawled and prayed and people sought to help me from all over the nation. God brought a doctor from Sussex that used nutritional medicines to heal the body as well and pharmaceutical, unbeknown to me God was using him to find the right tests and treatments to start to heal this broken body.

Over months and the two years, I fought having to use a wheelchair, this isolated our family, even more, my pride stopped me from going into one

What would the kids think, would they hate me? Be embarrassed? I certainly was. I had a disabled badge given to me and people started saying I looked OK on the outside, but internally my heart pounds, my head races and spins and my body aches and hurts like crazy. People would look “Why does she need a badge?”

So I fought it, for a long while until one day I was forced to use a wheelchair by the occupational therapist that saved my life. It was her courage to push me that got me out into the world again, the darkness was broken and although I was still sick I was able to go out for short times and see the world again.

These days were the darkest and hardest and I have many writings of those diary days which maybe one day I will write in a larger testimony. For now, though all that needs to be said is that God carried me and during the pain and crying and the crawling, I wrote and dreams of Manna reborn danced in my head...

Then in 2013 although still fighting my body my husband and I threw the dream to the wind, stepped out in blind faith and started Manna Academy mark 2! The rest of the story is so nicely put in the video here on this website, the in-depth version of this short testimony is coming soon, as God gives me the courage to write it all out.

Now a registered charity my husband and I are Christian workers living by faith in more ways than one. Now onto our ninth musical this year, we serve an awesome God!

Every day is a fight of faith, to put on the smile and strength of the Lord, invisible illness is hard - there is no outward appearance and you get judged a lot! However illness labels and diagnoses will never define our family, yes, it's the facts, however, I serve a God where His truth overcomes the facts and that's why we do what we do.

Manna is a dream, a destiny that no sickness or poverty could ever take I heard Arthur Blessitt say once 'God said to me what came first the sickness or the call?'

Well, I believe that before I was born He had plans for my life, and nothing the enemy can throw at us will ever stop our pursuit of those plans. I still stand in faith knowing He is my healer, I still stand to see the fullness of all that is in our hearts come to pass, I know it will because it's in my Daddy's heart more than mine.

Those in Manna are there because I refused to stay where I was.

For His grace is all I need.

Stay strong

Jai X

<https://www.potsuk.org>

<https://www.ehlers-danlos.org>