



Spunky or Faith?

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SPUNKY . . . ME? I was a little surprised when I was when I was labeled Spunky – why me? Was it just because I had a kid in a wheelchair? Or, have I been an example, a witness for others? If so, have I been the “right kind” of example or witness – after all, I am only human, I have choices just like you do, and I don’t always make the right ones . . . OK, so maybe “spunky” fits . . . ☺

After Don and I were married for 3 years, a blended family, yours and mine . . . we found out we were going to have a baby. We had just joined a new Church. I was so excited, thinking this would be “the” gel that bonded us all together. During my pregnancy, we found out that Daniel was going to be born with some challenges. I was pregnant during Lent and it was the first time for me to hear the Holden Evening Prayers – it was beautiful! Then during one of the hymn sings, we sang “Here I am Lord” – as we sang the words “Is it I Lord?” and “I will go Lord if you lead me”, Don and I just looked at each other and tears started streaming down my face.

During that time, we went through multiple ultrasounds – one of the first few, we were actually told they thought Daniel had a syndrome that would actually kill him before he was born and we were told of our “options.” I told them to never mention it again – we had seen our baby and we were having him! Spunky? Or Faith?

I finally started calling different situations “God things” – how else can you explain it? Another way to be a witness to others? Daniel was born by emergency c-section, a definite “God thing” - if I had had him naturally, he might not have survived. He came out pink and then turned blue – they resuscitated him and immediately put him on a ventilator to find out what was going on – another “God thing” – if they had known ahead of time what his actual diagnosis was, they may have “encouraged” not trying to resuscitate him (we were actually told that quite some time later). After making a diagnosis of Osteogenesis Imperfecta Type II and telling us that his prognosis was not good and survival rate was 2 months at the most, the medical professionals asked us “what would you like for us to do?” We told them to just make him as comfortable as possible, if that meant staying on the ventilator that was fine with us. During those first few days, our pastor came up to the hospital and performed Daniel’s baptism.

I remember going home without my baby – I remember the emptiness – I also remember trying to hold myself together for everyone else – especially our other kids and my Dad. When I was still in the hospital and had been given Daniel’s diagnosis – I remember laying there, with my Mom by my bedside and thinking about planning a funeral, instead of a baby homecoming. At that moment I was also thinking about my Dad – he had heart problems but was always strong in my eyes. He had retired as a School Superintendent, but still substituted because he loved school and children so much – and he

Texas Parent to Parent

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was working part-time, of all places at a Funeral Home in Rockdale. I remember asking my Mom if she thought **Daddy** could go through a funeral for his grandson.

I remember coming to Church the first time – again, **without** my baby, and being in the pew and standing for the prayers and hearing Daniel’s name lifted up in prayer – each Sunday - that turned into 14 months of Sundays (that’s 56 Sunday’s! – I had to calculate that one!) Remember we were told he wouldn’t be coming home? Well, he did come home at 14 months of age (yes, he spent his first birthday in the Neonatal Intensive Care Unit, but I still made him a birthday cake to share with the nurses, doctors and staff). I think it was approximately 6 weeks after Daniel came home that we did have that “public affirmation” of Daniel’s baptism. Daniel was still on the ventilator and we sat in the back of the Church so the noise of his many machines wouldn’t be “too” distracting. We watched the video of the service not too long ago – a very precious memory – and heard our pastor share a story in front of the Congregation – he said he had kept asking us to do a public affirmation of Daniel’s baptism because he felt he needed to talk to Don because I kept talking about when Daniel was coming home, and he knew what Daniel’s diagnosis and prognosis were - and that I might not be dealing with reality. We all kind of laughed about it, but I knew, I had that feeling that Daniel was coming home – Spunky? Or Faith?

Fast forward to 2013 – I still have 4 children and now 4 beautiful grandchildren! I bring them up, because I never want them to be “left behind” – I’ve made that part of my goal ever since Daniel was born. I never “expected” Daniel’s siblings to “have” to watch him, take care of him or be responsible for him – they still needed to be kids/teenagers themselves. They each had their own way of communicating and being with Daniel - I think they are typical siblings in a lot of ways, and Daniel has taught them a lot about life.

Have these past 20 years been easy? Absolutely not – that may be a shock to some of you, others may know a little of what our lives are like, but I don’t like to dwell on the negative – I can’t – Spunky or Faith? I know at some of the hardest times in my life – it has to be Faith. I have also learned to be “Spunky” when it comes to getting services for Daniel – and I can get pretty Spunky! I also know that at some of the hardest times in my life, I am that person in the poem “Footprints in the Sand”, because I can’t even walk, much less crawl, but I am carried.

I’d like to mention something that I feel very strongly about – People First Language! People First Language is just that – putting the person first – it says what a person **has**, NOT what a person **is**. Daniel is a young man who happens to have a disability.

People with disabilities are just that – people – they are Mothers, Fathers, children, friends, neighbors, relatives. We all have our different **abilities** – let’s look for those, our gifts and not how we are different.

Romans 15, verse 7 says: “Accept one another, then, just as Christ accepted you, in order to bring praise to God.” “Here I am Lord, I will go Lord, if you lead me.”

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