



## **So...podcast – Episode 1 Mum, Dad and Me**

*You're listening to So...podcast with John McKenna*

John: So, is the name of the podcast. I'm John McKenna, the host and producer of So. My plan is to have ongoing episodes that highlight interesting and diverse stories with different people.

“He looks like a little bird that's fallen out of the nest.” Those were the words from my grandmother to my mum the day I was born in hospital. I have a disability which is called arthrogryposis multiplex congenita. It affected all my limbs and I now use an electric wheelchair. The episode you're about to listen to are two conversations with my beautiful parents, Marie McKenna and Frank McKenna. I was really interested to hear from their perspective on what they thought when looking back on how things were as parents. I must of course also acknowledge my fantastic family. Tony, my oldest brother, David, Louise and my younger brother Paul. It's a great conversation, I know you'll get something out of it. Please enjoy.

So, I'm with my beautiful mother, hi mum.

Marie: Oh John, that's so nice. You're the first person to say that.

John: I'm sure I'm not. This is a conversation that I've been looking forward to having for a really long time because I know so much how you and dad played a big part in my life. For those people listening, it's really important to be able to enjoy this conversation to know some background. I'm a person that has a condition called arthrogryposis multiplex congenita which is a disability and has confined me to an electrical wheelchair and affected all of my limbs. There's been lots of surgery, lots of laughter, lots of tears, lots of decision making. It's really good for me to be able to have this opportunity and share with everybody the chat I'm going to have with my mum right now and we'll be talking with dad later on.

So mum, tell us about your family. How many kids have you got?

Marie: Well I'm the only girl with four brothers. So you can imagine how I was rather special in the family. Spoilt but not too spoilt, more loved. I then married the man of my life who I was, a school-aged girl almost, knew him when I was only 14 because he went to school with my brother, and then went to a lovely convent school where one was





encouraged to be either a teacher or a nurse, or of course, a good wife and mother. They were the ambitions of girls of my era. So I did that.

Was married at 20, had four boys and one daughter. So I was blessed, loved every moment of it. As one of my boys said “How on earth did you ever, ever manage looking after five children and you didn’t have to go to work and dad paid for our education?” I said “Well, just good management, that’s all.” I stayed at home and loved every moment of it.

So do you agree with that John?

John: I do, yes. How can you not agree? That came from the heart. So in 1962 you had me and I guess this whole conversation we’re about to have is just you sharing your own journey on how that was. So let’s start with, going back to, you were in hospital and the nurses have come up and said.... what did they say mum?

Marie: Well to begin with John, when I went to hospital to have you, I was two weeks overdue and you were supposed to be Katherine Anne because you were the most wanted of all my children to be a sister for Louise. But as it turned out you weren’t Katherine Anne at all. You came out as another boy and Louise wasn’t too proud about that when she heard. And then of course when the nurse brought me to you, they said “Oh, you’ve got a few problems with this bloke.” I said “Oh, what is it?” They said “Look, we’ll just get the doctor first of all to have a look at him.” And the doctor came in and said “Well, you have got a few problems with him. He’s just not like the normal kid you know. But anyway, he’s got good eyes.” That was the specialist paediatrician who came afterwards. But I looked at him and thought “Oh, you dear little fellow.” And as my mother said “He was like a little bird that’s fallen out of a nest.”

So it sort of really didn’t sink in that much. Then of course the priest came to baptise him and the priest said “What do you want to call him?” I said “I don’t know, he was supposed to be Katherine Anne but we can’t do that now.” “Well what’s your father’s name?” I said “Jack.” I said “Okay, we’ll call him John.” “And what’s the father-in-law’s name.” “Owen.” “Okay, we’ll call him John Owen.” I said “Oh that’s a lovely name.” So therefore that was how we gave you a lovely name John.”

John: So the attitude of the staff, medical staff?

Marie: I think they were pretty much upset. They were, you could tell. They were distressed. Because it was not often they get little babies that are not quite as well formed as others. One particular poor woman said “What are you going to do with him? Isn’t





there a place that he can go to, or they have babies like that?” And I was a bit horrified so I told the matron and she said “Well that’s wrong.” But looking back I think the poor girl, she was only a young nurse. She didn’t know what to say in situations like that. But anyway, the rest of them were wonderful, absolutely wonderful. I had so much help from friends, I really did.

John: And I think that’s like any situation where something wasn’t planned, comes up in your life and you then talk around who’s there, who can you talk with. So your brothers and mum you’ve spoken about. Girlfriends, how did that go? Naturally I was your third child so you’d go to catch up with other mothers and talk about the kids.

Marie: You were the fourth child.

John: Thank you. I just got four fingers held up by my mum. I was never good at maths mother. So as the fourth child..... what I’m getting at is your girlfriends who spoke about their kids. Did you find their attitude changed towards you where they had to bring up me?

Marie: No, not at all. I’ve just had the best help. All my girlfriends were the first to say “Bad luck, but never mind we’ll help you, we’ll help you.” They were upset themselves but all took it very well. That’s the sort of friends I’ve got and still have got.

John: That’s right. They definitely played a big part when it came to my hospital time and the visits and all that.

Marie: Oh yes, yes.

John: So we’ve done the hospital thing and we’ll go back there of course because there were a few visits. But the overall system, once again we are talking about back in 1962 of course. How did you feel? Did you expect more support from government and organisations?

Marie: No I didn’t really. We were always able to cope on our own bat. The health sister, the local lady, she came to visit me, more so than me go down with John because apart from that I had three other children. We were not far and she said “Don’t worry about coming down Marie, I’ll come up and weigh John.” She popped up, had a cup of tea with me and then went back and life went on with that type of expectation. It wasn’t too much at all. We just got on with life. Of course keeping John healthy, that was the main thing, which he was a very, you were, a very healthy child. Very healthy.

John: That’s good.





Marie: And hardly ever cried. You just gave a little whimper when you were uncomfortable. No, you were marvellous. You were bottle fed of course. You weren't breast fed because that suited everybody.

John: For sure. There were lots of decisions that had to be made in relation to corrective surgery.

Marie: Well before that you were put in a little cradle to make your spine a little bit more, we hoped, straightened up, being put in a cradle for that. Well that was no bother. Then you were given, your little feet were clubfeet so then you were put into these little braces to keep your feet straight. All that type of manoeuvring was done when you were very little. You wouldn't remember anything like that?

John: Not at all, no.

Marie: And then as you got older, when the old Children's Hospital was finished, you were in the intake of the brand new one but you had pneumonia. You were very sick and inclined to be a little bit chesty. But you got over that too. From then on you had a very good surgeon, Peter Williams, and we went by what he suggested the whole time just from month to month or year to year, and just did what he suggested which we hope was a good view. I don't know. Sometimes I often think it would have been better to have left your leg straight or the way it was. But anyway.

John: It's all history now.

Marie: That's all history, yes, doesn't matter.

John: But the whole thing around corrective surgery, it must have been a really tough decision sometimes with you and dad to be able to decide what's going to work, what's not going to work.

Marie: Well we put our faith and trust in the surgeon because what else could we have done?

John: And it has worked out really well, the surgery. Was it an adjustment for you in relation to the family dynamics because of course I was just one of the children? So you had to basically work with them and make sure they weren't being affected too much.





Marie: Quite frankly, I didn't give it too much thought because our family was a group. Each one of them had their own little lives to lead and went on accordingly. No, it never gave me any problems at all.

John: That's good. Decisions around schooling?

Marie: Oh yes, there was a bit about that. I had a thing about you having to go to a school, as you know, with all these disabled children who weren't quite as bright as you were. I did go around to quite a few schools and said "Could John go?" And it was a case of "Oh no, we've got staircases here, it wouldn't be that suitable." So you went to Marathon and that was good when you were only a little tot I think. I'm trying to remember now when you were at Marathon. That was junior school. It was more when you were going into senior school that I was looking for a school, because Marathon was excellent for you at that time.

John: That was a special school.

Marie: Yes, special school, and it was excellent. The blue bus came and picked you up every morning and that taught you the basics like preparing Brussels Sprouts which I still remember [laughing]. Every time I cut a Brussels Sprout, I always think 'Oh John told me that I must put a cross at the bottom of them.' Do you remember that?

John: I do remember that actually.

Marie: And then I used to give you the job of peeling garlic all the time. You used to say "Why do I always get this job?" But you did it so beautifully.

John: Thank you.

Marie: Do you still peel the garlic?

John: Still do the garlic, yes.

Marie: Good. Anyway, then I went to the different schools and you went finally to St Aloysius.

John: That was a normal school.

Marie: Yes. And then after that, when you went into senior school, you went into Bentleigh St James, the De La Salle Brothers, where you finished your education there.





But I had, if you can remember, all those lovely volunteers who actually picked you up in their car and dropped you home. We had a roster going and it was really great.

John: As far as my brothers and sisters, I keep going back to them because a disability in a person's family can be quite disruptive because you've also got other sporting commitments and they want to have their lives and do other things. I'm the first person to agree that I come from a very loving family. There's no conversations you've had to have at different times about getting the balance right, if that makes sense? You know you've got to love all the children equally.

Marie: Yes, yes. Not really, no I didn't. I think every one of you are all just treated, and still are, exactly the same. Always have been. I suppose that comes from my upbringing. We were all treated the same at home too. I had a wonderful family. No-one was picked on or anything like that. We had our normal little problems but we got over them. We didn't make an issue of anything which we still don't make an issue of anything. Perhaps I'm not a worrier.

John: There's one thing I do want to talk about and this is, we laugh about it at different times, but I think the older I get and the more I reflect on it, there are times where a decision was made where I'd go in for a bit of respite, into an institution and the whole family would go away as a family unit on a holiday. Like I said, I've got mixed emotions about that but obviously I can see it's now had no negative impacts. How did that come about?

Marie: When we were first married and we went into business and we were very busy, we went to one particular doctor and he said "Now look, you're going into business, what I suggest for your own sanity and marriage, this was before I even had any children, make a point of taking two weeks' holiday and go away somewhere and forget your business plans or whatever you're doing. Just remember what it was like, just the two of you together." And we did that every year. Had two weeks' holiday, whether it would be getting in the car and just going to local areas. We didn't have the money to go interstate or anything like that. We did it all the time.

So of course when you were born, and then Paul came after that, we still managed two weeks away. But of course having our property at Pyalong, everyone came to Pyalong, that's where the family holidays were every school holidays. But I think there were some holidays I felt for you to go into Uralla or a girlfriend looked after you. The same applied for young Paul who came after you. People offered to look after your youngest, and the same I offered to look after other people who had big families. If they wanted to go away, we sort of shared giving our kids away in holidays and looking after them. Well it's the





same as that, only you happened to go to Uralla because I didn't feel as though many people could look after you as well as what they did.

John: But obviously too, and it makes a lot of sense to me as an adult would look back on it, to go away to the beach with your family knowing that that would have been very challenging, having one of your children in a wheelchair but at least you could go for drives and get onto the beach as a group. And I fully appreciate that, it makes a lot of sense. So that's really good.

I'm loving this chat and I just really hope that people listening also can appreciate, sure 1962 and I'm 57. Is it rude to ask, I'm just trying to avoid people having to do their sums, but you're 80 something?

Marie: John!

John: You don't ask that question do you?

Marie: I don't mind because I'm going to be 85 next Sunday.

John: Are you really?

Marie: Yes, so don't forget it's my birthday.

John: Thank you mother, I love you.

Marie: I can't believe it myself that I'm 85.

John: And I guess, you married comedian Frank McKenna, we'll be talking to him soon. But comedy has played a big role or humour to get through stuff has it?

Marie: Oh I think you've got to take life a little bit easy. People are so.... in my opinion they worry about things that they've no need to worry about because often these things I was told may never happen. So don't waste your life worrying. I get concerned about things but worry doesn't get you anywhere. You just do something about it. Don't you agree there?

John: For sure. And for other parents listening who have got a child, it may not be disability but have their own challenges, what's your words of wisdom that you'd like to share to the world about happy family and I guess in particular, being able to identify that point of difference that their child has but not necessarily let it become too disruptive.





Marie: I think you just have to think, if you've been given a child that's got extra needs, you should be flattered to think that the good Lord has chosen you to look after that particular child and be proud of the fact.

John: Mother, I love you and thank you for having a chat with me about this.

Marie: Oh thank you John, that was so lovely. I think we've had our little talks before about this haven't we?

John: They've never been recorded.

Marie: Oh, is that what it is.

John: Now the world can hear.

Marie: Lovely. Alright darling, well thank you. I'm going to make a cup of tea, would you like one?

John: I'd love one, thank you. Bye.

Marie: Right okay, bye.

John: Dad, as you know I've already had a chat with mum and it's really great that you're able to be with me right now and have a similar conversation. You're going to share your thoughts through a different lens. As I said to mum, it's really important that I've always wanted this opportunity to have a chat but more importantly be able to share with everybody, because I'm a very proud individual and I know it's because of you and mum that have guided me and made the right decisions, and I love for that and I thank you.

So dad, kicking off, I want to just talk about any opening remarks or having a child with a disability, life changing, or how did you prepare yourself?

Frank: Well the one thing that is in my mind and I was from a large family who also had large families, so the ability to mix with relatives at different ages and different places were certainly helpful because of the problems that people had over the years that were not uncommon. So when you arrived and had certain difficulties, it was a lot easier having people that supported our family over the years and the family that were in the one building for so long and shared day to day activities and ideas of what should be done and how it should be done.





John: Decisions around my education and surgery, I guess, did you reflect with them or talk with them about that? How could you share your journey around those decisions?

Frank: Well being the youngest male in the family I had very little opportunity to have an opinion. Most of it was decided by the older members of the family and medically it was quite unique that we had a doctor uncle who was very well known, Dr Arthur Haywood, and he was born on an island off Hastings. He became a doctor. He opened a practice in Hastings, he ran the Hastings Hospital. He was involved in the Frankston Hospital, the Mordialloc Hospital and also worked at the Alfred Hospital.

So during our early childhood at home, if there was any sign of any illness or unwellness, uncle Arthur was inclined to call in to our home in Ormond and if someone had a sore throat or bad ears or sore leg, uncle Arthur would say “Get him this” or “Hop in the car and I’ll take you down to Hastings and we will fix it.” So it was a different situation to a lot of families where we had a very positive medical person available. A couple of times a week he used to call in and say hello. He had a large dairy farm down at Windrift and he would call in with a couple of litres of milk on the way to the hospital.

So my family feelings were a little bit different to a one and two child family with no close relatives.

John: So what role did he play, knowing that you had a son with a disability? Was he able to share any thoughts on that?

Frank: Well as the years went by, we weren’t as involved as you would understand. He had less trips to the Alfred Hospital and we were seeing less of him. So my involvement medically was with the local Dr Britton in Bluff Road, Sandringham, who was quite close to where our business was. We saw him regularly and he kept in touch and obviously he was the first to be aware that there was some problem with the arrival of our next child.

John: And the fact that it was so rare dad, arthrogryposis multiplex congenita. Did you find that the general system or the people that you were hoping for answers, weren’t giving it to you? Was that a frustration at all?

Frank: It wasn’t a frustration. It was an awareness that the particular problem wasn’t common and treatment would be carried out with the idea of improving that condition. Naturally we would ask questions and they would say “John has gone to the hospital and we hope to have him back in the next couple of days, and we are treating this by doing that.” In those days it wasn’t like today where you can get a medical report. It was more





the doctor popping into our home or shop and saying “I’ve seen John this morning and he seems a lot better. There’s a problem with his back, or neck or arms, and we are doing this to deal with it.”

The next step came when he then cared for a specialist, Mr Peter Williams, which again was the only other person that we dealt with over the years. We weren’t dealing with a group of medical specialists. So it made life a lot easier from everyone’s point of view that we were getting reports from Mr Peter Williams as to what your condition was, what could be done and how well it was done.

John: I see. And getting slightly off topic, there’s so much that I could speak about as how much of a beautiful father you’ve been with regards to the extra effort about putting the wheelchair in the car. There were no wheelchair taxis. I don’t want this to be about me, but do you want to reflect on... I don’t remember you, very rarely, saying no. So as far as being a great dad, you were there and you would go to the effort to pack up the bloody heavy wheelchair and put in your car and take to work. Any times there that you want to reflect the good, the bad, the frustrating or humorous?

Frank: I just wonder how we put five children, two adults and a wheelchair in the one car on a regular basis.

John: [Laughing] Yes.

Frank: But that’s what happened and we were fortunate that we were able to do that and travel around as we did, going to the country farm property at Pyalong where we just loaded it up and got up and unloaded it, took all the things out and had a very active and pleasant time.

John: I was never treated specially in your eyes dad, which is beautiful. I was one of five kids which is great.

Frank: Well that was the fortunate part of your condition, that you were able to accept the fact that you had certain problems but you also accepted that you were in a very wonderful family where they also accepted your condition and were able to contribute by assisting and becoming part of your day to day living.

John: Dad, there are other people listening to us talk right now and they might have a child that’s got challenges. It may not be disability, but words of wisdom you’d like to perhaps share to other parents? I know we’ve been talking about back in 1962, it’s a different world now, but if you were to pass on some thoughts to other families, what would they be?





Frank: Well the first thing I would try and do is get them off their mobile phone.

John: [Laughing]. Keep going, I love this.

Frank: So we could talk. But I believe that the family environment is still possible today and we know lots of people that do have it. Where the family environment isn't there, there's generally a breakdown in some relationship which is very hard to overcome.

John: Thank you. Dad, thank you. As I said I love you for all your guidance and where I am right today and I enjoyed the chat.

Frank: Thank you John. It's a delight to be with you at any time. You're most entertaining, you're a very wonderful brave person and admire you. We thank you for the way that you have accepted the family and being part of it and can only hope that the future is just as happy for you as it has been for us.

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