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**GRACE FOR ALL**

***Interview***

**Noreen:** “My daughter has an intellectual and physical disability and it’s been really rough, but my faith in God has kept me going through it and He will continue to. I believe it.”

**Celia:** Looking forward to the birth of a baby is usually pretty exciting. We think about watching them grow and develop and look forward to the things we’ll do together. We can even imagine them with their own family in the future. There’s a lot of expectation. So how do you cope when you discover your baby is born with severe disabilities and those expectations will never be met in the way you imagined? Today I’m talking with Yvonne and Noreen who both raised children with disabilities.

**Celia:** Noreen, how did you feel when you heard the news that Julie would be unable to talk or walk and that she would be dependent on you for everything?

**Noreen:** Well it was the shock of my life and it was devastating for me. It was like like a death. It was a grief. I mean I had to cope with the fact that this child who we just all loved already was not going to ever do anything that other children would do. She wouldn't go to school she wouldn't learn. She would look different she would be whatever. And it's a dreadful experience for me it was terrible at that time and I found it very hard to deal with. It took me months to get over that period of my grieving.

**Celia:** What about you Yvonne, did you also have a grieving time?

**Yvonne:** The grieving thing is a continuous thing and it keeps rearing its ugly head. You think you're coasting along really well and then something happens and you think I can't do that because James can't do it or I can't do it. And it's because of his disability basically. And so you're always trying to negotiate around his disability. And it means doing so many other more complicated things compared to what other people need to do to achieve the same thing. And that's a grieving thing.

**Celia:** Yvonne, you knew early on that James had learning difficulties but it was some time before you knew his actual condition – Angelman’s Syndrome.

**Yvonne:** I guess we didn't realize how severe it was going to be. And even for years we wouldn't have realized that because we still had expectations and were still trying to put effort into him learning to talk and to develop skills. He was 17 when he was diagnosed with Angelmans syndrome. And then we found out that he's not going to talk because none of them do. We used to feel a bit guilty that we didn't put enough effort into trying to do these things with him. But he was quite a delight to look after and he was a very happy little kid.

**Celia:** Noreen you and your family were living in Papua New Guinea as Christian missionaries at the time Julie was born. Did her brain damage affect your relationship with God at all?

**Noreen:** I cried buckets actually in those days. Why did God let this happen? The New Guineans who we're with us said “what did you do wrong”? That was the awful part. What did you do wrong? And I looked at myself and I looked at us and thought what have we done wrong? But immediately I remembered the words from John about the blind man who came to Jesus. That was one thing that spoke very clearly to me. Why was the man born blind? And it was because God's glory was to be revealed, not because he'd done anything wrong or his parents had done anything wrong. That was the start of a comfort for me and the Word of God was just comforting right through. I would yell to God, I was screaming to God! I was crying why aren't you healing this child because God heals? You know he can heal. And people were saying “why don’t you pray?” I’m praying! What can I pray? You know the child wasn't getting any better. And I can see that God wasn't going to listen to that prayer. Now how to accept that? Where are you God? What have you done to me? And it was all very traumatic at that time. Being away from home wasn't that much good for us either. But then God kept leaving little messages in my heart like don't be afraid, don’t be upset. You know I'll comfort you, I'll help you. And he was a rock. Even though I couldn't feel him, I couldn't see him, I couldn't see anything happening. He was like a rock that was keeping me there, anchoring me down. And he healed me. He healed me inside so that I was able to accept what was happening.

**Celia:** This is Messages of Hope and today I’m talking with Yvonne and Noreen about raising intellectually disabled children. After hearing about the initial grief of coming to terms with their children’s disability, we went on to talk about the everyday issues as their children grew older. Yvonne, you’re married to Colin and have 3 other children. How have James’ difficulties affected family life?

**Yvonne:** Colin was working when James was little and I was looking after him. We had two more children after that. We had four little ones. As soon as Colin got home every evening. I would dump James in his arms and he would take him for a walk. That was my time out from James. I guess over the years, if we were angry with each other we would take it out on James. That kind of thing was happening. I was aware of that. Wasn't really James's fault. It was more the whole situation. Yes. And there's just so many things with trying to develop his skills that are just so repetitive. It's just awful. Toilet training a person for 33 years. It just never seems to end! And you know you sort of get to that breaking point. It's nobody's fault. It’s not Colin’s fault. It's not my fault. Not James’ fault. And then I think our two youngest ones in lots of ways they had to bring themselves up. I don't regret having them because they're wonderful kids but they had to be a lot more independent than our eldest.

**Celia:** Noreen, can you tell me how people outside the family have reacted?

**Noreen:** I was away from home. We were in New Guinea. They would say “It’s Julie’s time” when she cried, “It’s Julie’s turn to cry, it’s her time.” They just took her as she was. In Australia people have completely different attitudes. You know you've got to be pretty, you’ve got to be this, you’ve got to be that, you’ve got to be able to do things, you've got to have something that marks you as important. And the thing that marks you as important is your abilities, your inabilities don't count at all. They don't see anything in that person as a precious thing. They just see it as a disabled person with lots of trouble. But you know inside that disabled person there's a child that we loved dearly and that child is a treasure in it’s own ways. You can't explain that treasure to anyone else. It's just there. It's a pity we have to see someone do something wonderful before we see that treasure that's in a person and I think it's God given. It's part of what God has made us. James is a treasure, a complete treasure in his own way but he's still hard work for his family, you know. Julie is too, she’s just given us and other people lots of love and lots of joy and laughter. And she's nice but she's not easy. Life is not easy.

**Celia:** When we’re faced with daily challenges, especially ones we can’t fix, it’s difficult to see beyond the struggles. Yvonne and Noreen had children born with an intellectual disability. Their children would need constant care for the rest of their lives and are currently in their 40’s. Amongst all the struggles and frustrations over the years has there been anything that’s inspired you?

**Yvonne:** James is probably the only person who loves me unconditionally. So even when something goes wrong he wants to make up, within minutes. He is aware that something's gone wrong in our relationship. Got to have a hug. And he’ll be upset until that happens.

**Celia:** And what about with Julie, Noreen?

**Noreen:** It is an unconditional thing. There was nothing that she could do to make me love her more or less. I mean she was there. We loved her and that was it and God is exactly the same with us. We do such awful things and such stupid things at times but God keeps loving. There’s nothing that I can do that makes him say you're no good.

**Celia:** Yvonne,what would be one thing that you could say you’ve learnt through your experience over the past 40 years or so?

**Yvonne:** I think one of the most wonderful things that I've learned and it’s become really concrete for me, is the way that God works in people. How his grace works in people. That he can take James who can't communicate and make him this wonderful outgoing Christian. And I hold baptism as something that's really special because James was baptized and we see God working in people all the time. So many people with disabilities just accept God and they respond. He loves them and they know it.

**Celia:** Can you explain a bit more about what baptism means for James?

**Yvonne:** Well because of his baptism we know that God has made himself known to James and he continues to work through him. He knows the difference between a church function and a different kind of a function. Church is where you go and everybody prays and worships and we get to go out to communion and to shake hands with everybody when we pass the peace. He knows that. And we haven't taught him that. He's learned that by being there and participating. There's a member of our congregation who says that James is liturgy in motion. It's just a wonderful way of thinking about James because he listens and he responds and he does the sign of the cross when it comes up and as soon as pastor says let us pray and everybody's still thinking he's got his hands up here. As soon as the communion starts he knows, he's ready. And the singing, he can't sing but if I'm not singing, why am I not singing? He makes me turn my face, come on sing! And he stamps his feet and he claps in the songs. And the song leaders say, “thank you James,” at the end of the song. And that's God working through him.

**Noreen:** For me baptism for Julie is that she is safe and secure. She's in God's hands. And that's a wonderful, wonderful feeling. So whatever else happens to her life she's always there in God's care.

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