

# Our Greatest Teacher

Ken Robinson interviews Glenn and Adrian O'Dea



In writing about grief and loss wanted to talk with Adrian and Glenn O'Dea of Perth. Over thirty four years they have provided a living example of grace, love and an optimistic spirit in managing a situation that has shattered the dreams and sometimes the families of many young couples. A glimpse inside their lives and experiences may add inspiration and courage to many of us facing some of the tough experiences in life. **Ken Robinson:**

**Ken:** Thanks for agreeing to share some of your experience when Ross and Melissa arrived in 1987. You had a little infant, Steven, and you learned you were pregnant with twins. Would you please share some of that experience?

**Glenn:** Steven was 2 years and 6 days old when Ross and Melissa were born. When they were 4 days old the doctor came and told me that he thought Ross had Down Syndrome. A few days later the test results confirmed the diagnosis.

**Adrian:** Were you still in hospital when we got the results?

**Glenn:** Yes - I was in for 10 days because they were 2 weeks premature. Also there were some problems feeding with Ross, and I was going through grief after the doctor's visit. You think you are going to have two normal, healthy children and then when you don't you get a big shock. And so I did go through all those stages of grief. Also for me it was a very public thing because I had the twins in the hospital where I worked as a nurse. So all the staff knew me. There wasn't a lot of privacy.

**Ken:** What were your first reactions to hearing the news?

**Glenn:** I accepted it in my mind straight away because I knew about Down Syndrome. But it is different actually having a child with the disability. People can tell you about it, you can think you know about it, but until you go through it you don't really know.

**Adrian:** For me - the hardest thing I suppose was the bombardment of information. Oh mate, it was huge. I was looking after Steven at that time and so I just basically took it upon myself to be a real strong support for Glenn and Steven and the twins. We were dealt these cards and we had to play with them. So I did that.

One of the real blessings is that the church family rallied around us and really supported us. There were several people that came in to help. "Righto Glenn - go to bed." They'd get dinner and look after the kids until I would come home from work.

I also remember very clearly when my mum and dad came down from the country and visited at the hospital. We said to dad "We have twins and Ross has Down Syndrome." I looked at his face and he had no idea what I was talking about. As soon as I said he had mongolism - mate, his face just went gaunt. I remember Ross being in the humidicrib.. I said "Come on dad let's go and have a look at the twins." We were sitting there and I said "Are you just checking him? He has 5 fingers on each hand, he has 2 eyes and 2 ears." Dad couldn't understand what Down Syndrome was about. So over a period of time we educated him. I could see that inside he was elated because he had grandchildren but he didn't display it.

**Ken:** So you were also managing the feelings of some of the extended family?

**Adrian:** Absolutely I was, and if I had an opportunity to share I would share it.

**Ken:** Where did you get the strength to do that Adrian? I'm imagining you being in shock yourself.

**Adrian:** Probably my country upbringing. You know if there is a tragedy you just get on with it. I was a prayerful person - but it's church and my understanding of Christ and getting on and doing it. I had quiet times - "How am I going to do that?" I wasn't a very emotional person back then. Now when I watch movies a tear will run down my face, where in the early days I would think "What's this rubbish all about?" So you do change.

I recall the support for you Glenn. I remember when you were in hospital the Down Association's Jackie Softly came and spoke to you.

**Glenn:** The year that Ross was born the W.A. Down Syndrome Association had only been going for 12 months. Jackie Softly, who started it in WA, actually started a hospital visiting team and I was one of the first people they visited. She came and visited and shared pictures of her son. She just said to us "Ask me anything you like." And so we did, which was very helpful.

**Adrian:** We formed a bond and a relationship with her.

**Ken:** Were there other difficulties in those first few months?

**Glenn:** I think one of the hardest things was having to tell people that didn't know. That's why we ended up having it announced at church because that was easier than having to tell everybody individually. I've observed different points of view over the years and I think it is better to tell people than not tell them and try to hide it.

**Ken:** Someone might hide it because of embarrassment or a sense of failure?

**Glenn:** Yes, that's right.

**Ken:** Were there different challenges with Ross from early on?

**Glenn:** When they were first born there was only a small difference. I breast fed Melissa and bottle fed Ross. A Down child has a problem breast feeding, similar to having a hair lip cleft palate. Therapy for that wasn't available then. I've actually been able to help a lot of people who were made to feel guilty about not being able to breast feed. I bonded just as well with Ross as I did with Melissa.

**Ken:** I hear a lot of emotion when you say that. That's really meaningful.

**Glenn:** Yes. Some people are made to feel guilty about that, but the bonding can still happen.

**Adrian:** We developed routines to cope. I would get up very early in the morning, have all the washing on and out on the line (including all the cloth nappies) and breakfast all done. When Glenn had her shower she'd come down and it was all made for her and then I'd go to work. When I came home I would take over just to give her a break. That just became a routine.

**Ken:** How come you two were so accepting of the situation and willing to just get on and make it work?

**Glenn:** Probably because of our parents.

**Adrian:** Well according to our statistic we should never have been married. Me from the Bush, a real rough diamond as opposed to a young city lady growing up in a church environment. I had no idea what I was getting myself into, but the decision was you go 100 % or you don't go at all.

**Ken:** And that's a value that I've heard you say you inherited from the bush, from your family.

**Adrian:** Yes. Now I would say it's about respect, the worth of persons - and as you grow older you become sensitive to other things and that's maybe Spirit or God talking to me. One thing that really impressed me - Steven and Melissa would look after Ross and look out for him. They had an extra sense of compassion.

**Glenn:** Steven was looking after Ross from twelve.

**Adrian:** We left Ross for the first time in 2007 for an overseas trip of 42 days in the US. We had respite set up for Ross and we got on the plane and we both said together. "Well it's out of our control now." When we got back, I can remember this as clear as day, we were coming down the escalators. Ross was with his carer running late. Ross came in and said "Mum, mum, mum" and gave her a big hug and then said "Where is dad?" and I was over at the baggage carousel. He came and gave me a big hug then he turned to his carer and said "Let's go now". Unbelievable!

**Ken:** What did you feel about that?

**Adrian:** I had confirmation that for the past 42 days that we had been away that Ross had been looked after. I knew he had been okay.

**Ken:** When you got on the plane, going for 42 days, Ross was 20. For 20 years you hadn't really had a day where you weren't feeling responsible?

**Glenn:** Yes. When I was at work some of the younger girls would say, "Why can't I have holidays and why can't I do this and that?" Another woman and I both said "Well for 20 years we brought our kids up, and then we went and had some fun." With Ross we were having physiotherapy and occupational therapy with him from six weeks of age, so it was full on from then. He would do therapy even when he was sick. At 6 months they started speech therapy as well. So there were always appointments.

**Adrian:** He travels with us now and opens doors for us. We were in Hong Kong and were given a pink bag with some Chinese writing on it. He carried it wherever he went. We had no idea what the bag said for a long time. Then someone said "Do you know what it says on the bag? It says: "Jesus loves you". When people would get in a lift and see Ross with the bag they would smile and Ross would wave back at them. That would break down a lot of barriers. Ross breaks down a lot of barriers for us with regards to people spending time with us.

For the average family their children are becoming independent by 20, but Ross is still with us at 34. So now we are trying to put things in place for Ross as we are getting on and must consider what happens to him when we are not around.

**Ken:** Did you ever question why us? Why me?

**Glenn:** Yes, it crossed our minds at times. Disability services were helpful and always very positive in stressing - "This isn't your fault." The type of down syndrome that Ross has got is the common garden variety. And there is no known cause for it. So how can you blame yourself for something where the cause is unknown?

**Ken:** Ross has become a very special member of our congregation. There are many stories. I remember seeing a video of Ross' baptism and Ross in the video is leaping into your arms in the baptismal font. Those things become legend in the congregation. That becomes part of who we are. That isn't just Ross' story or your story. That's our story too as a congregation.

**Adrian:** I can remember in the Woodlands church in a service Ross was asked to collect the offering. As people gave the offering he would lift his right hand up and put two fingers on his chin and then put his right hand back to the plate. I could see people wondering what that was all about. After the offering I got up and explained that this action is sign language for 'thank you'. The next week when he collected the offering people would sign 'thank you' back to him. It was about educating people - giving others an understanding of how Ross communicates. He doesn't use sign language as much now because once he started using sign language he stopped talking. We had to de-emphasise that and prompt his oral communication. So they are the sorts of things we all had to learn.

Our support has been church. That's been a stable influence.

**Ken:** Over the years we have continued to see the unique role he plays in the congregation.

**Glenn:** I remember one time that Adrian and Keith Smith were preparing to lead a service. They were in the hall and they were running late. Everyone was seated waiting. Ross got sick of waiting so he jumped up the front to the microphone and said "We are going to sing Jesus is the rock." Someone quickly looked up the number and called it out. Cheryl at the organ quickly started playing. Adrian and Keith heard the music and singing. Adrian said to Keith "They are starting without us! What's going on, did you choose this? We'd better get in there!" Ross had started the service!

**Ken:** I remember being in Perth for his first communion and wondering if he would be able to manage that. It was obvious it was important to him. And there were questions before his baptism. "Should you really baptise someone who has Down Syndrome?" Do they know what they are doing?"

**What would you say to that now?**

**Glenn:** Really when you are baptised you are just really at the beginning of your journey. And you really only have to have a basic understanding. In Ross' case it really is only a basic understanding. God doesn't judge you just because you don't have the full understanding. It's important that you just want to make that commitment.

**Ken: So what difference has it made to Ross that he made that commitment?**

**Adrian:** It's probably now routine for him. I remember at his baptism. All you could see was my hand like a periscope out of the water. I had to go under the water with him. He came out and shook himself like a shaggy dog. Sometimes when I look at someone close to me I can see the spirit in them. I can feel or sense that Spirit in them, that contentment. He was all of those things. Just at that time he was so contented. By experiencing that moment with him I couldn't but not recognise it and be really blessed by it.

**Ken: You have had a very different life than the ordinary because of your responsibility. You have times in the week now when he has his routine and you can be yourselves but for the most part he has been a major presence in your lives. You have had a big responsibility, to be alert, to plan that has never gone away. "How has that life with Ross changed you?" What difference has it made to who you are?"**

**Adrian:** From a spiritual aspect it has really, really increased my discernment and I have a sensitivity to a lot of things I can't explain. You are listening, and aware of him even if he isn't in the same room. Because his body is 34 years but his mentality would be six at the very most. So to understand that and watch him is a constant that becomes part of me. I can go down the street and see someone and instantly recognise that they aren't ok. I'll ask "Are you ok?" This comes also from my bush background, as a country boy you talk to anyone and say hello. There are times when I've really struggled and he brings me back.

**Ken: How does he bring you back?**

**Adrian:** Just the way he does things. His peace, his simplicity in life. Everything is simple.

**Glenn:** He does have some of Adrian's sense of humour.

**Adrian:** A lot! He comes out at night with the dishes ... "Good morning"... or he will say "Hi cutie pie."

Where would a 34 year old person go up and say cutie pie to their mum? That is the child in him and should be the child in every one of us.

That should be all of us but other things take over.

**Ken: Glenn, how has Ross changed you?**

**Glenn:** I guess to be a less judgemental person. What you see on the surface of people isn't always what they are like.

**Ken: What would you say to complete the sentence - The best thing about having Ross these 34 years is.....?**

**Adrian:** Is Ross - I wouldn't change it for the world. Glenn and I are now retired and we can't just go and jump in the caravan and go. We can't do it. We have to put everything into place for him or take him with us. Since doing the 42 days in the US we've picked up the travel bug and so he comes with us and is our key to the world. He just opens up a lot of doors for us.

Because other cultures don't see his Down Syndrome and because he is a westerner they are curious and they are fascinated in experiencing him as he is. For me I wouldn't change anything. I remember coming back through an airport and handed over Ross' passport and the guy was flicking through the pages "You've been to more places over the world than I've been in suburbs in Perth." But he is a joy to take. He just is a joy to have.

One of the learning experiences is that we have always expected him to be happy. every single time - because of his loveable, friendly caring nature - and he reminds us that it's ok to have an off day. That it's okay for him to feel unwell. It's okay for him to have a headache. He is sort of a good leveller. He is grounding.

**Glenn:** I think the hardest part will be when he leaves home because we have had a child at home a lot longer than a lot of people have. Some parents say "I cant wait for my child to move out of home." I'm not one of those parents. I know they have to eventually. We have to look at it realistically. I think the joy that he brings is my thing. When he is not there we notice how quiet it is, and yet he's not a noisy person all the time. He's the quietest of our three children but we notice when he is not there.

**Ken: So it's been a community experience with the disability services, the association people and with the church community and others. It's the community involvement that you are more aware of than a lot of people would be.**

**Glenn:** Yes that's true. You need all that support because you are definitely not an expert on Down Syndrome when you start off.

**Adrian:** You are not an expert now.

**Glenn:** NO... we're still learning.

**Ken: And Ross has been one of your great teachers.**

**Adrian + Glenn (laughing):** Oh yes!!

This edition of the Australia Herald deals with sensitive subjects, including grief and loss, material that some people may find distressing.

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