

LIVING WITH DISABILITY:

FEELINGS, FAITH AND FELLOWSHIP

Talk presented by Moira Byrne

I vividly remember one of my life-changing moments. Waiting in a physio room at the Women's and Children's Hospital in Adelaide, I read a developmental chart, and realised my nine-month-old daughter Caoimhe was significantly delayed in almost every area. It was like a punch to my heart. Caoimhe's ongoing global developmental disabilities were confirmed shortly afterwards.

When I first was pregnant, I was jubilant. Matt and I wanted children and were pleased things went to plan. Things hit a road-bump when I inexplicably experienced a threatened miscarriage.

But, life continued and we welcomed Caoimhe into our family. But things did not proceed smoothly after her birth, with feeding difficulties and her failure to thrive. Over time, it became apparent that many usual milestones were not being met and investigations began. I don't wish to revisit the details, or those early feelings, but I felt sadness, loss, and in particular, a sense of astonishment and

almost injustice. Why did this happen to our daughter, our family? Self-blame and sadness followed confusion and resentment.

Some questioned us, as if to discover a reason for our tragedy or to assure themselves it could not happen to them. Others, in an effort to comfort, said we were special or chosen or strong or faithful or that there would be a miracle - and that was 'why'.

To be frank, I found these comments unhelpful. I'd never really questioned why things happened, and living a reasonably uneventful life I blindly nodded when people talked about 'reasons' as if lives are preprogrammed.

But my life's events with Caoimhe changed my faith profoundly.

Now, I believe it's up to the individual to create their own reason. After I came to terms with Caoimhe's

disabilities, I believe I became more sensitive, justice-minded, and inclusive. So, to rephrase something I read recently - I'm not special or chosen because I care for Caoimhe; rather, she's inspired me to be someone more than I was.

For me, faith is finding God in the midst of life's events, be they joyful, mundane, or traumatic, and continuing to allow God to love us and to love God and others.

I see God in Caoimhe. She is gentle, patient; she does not envy, boast, or dishonour others; she is not self-seeking or easily angered and she keeps no record of wrongs. She trusts and perseveres. Sound familiar?

And I wish others could see Caoimhe as I do. She's introverted but she enjoys a bit of interaction. Although she doesn't always respond, I wonder what she understands and what she makes of her treatment. That's not to say I consistently live up to this

standard myself. There are very few things Caoimhe can do without help, and sometimes it's too much emotionally. There are stresses involved in caring for someone with significant personal needs, and I tire of dealing with stares and comments, or educating people about the finer points of disability awareness, etiquette and inclusion. There's also an ongoing loss for me when I see others reach milestones that she will not.

But I also weary of being seen as a caregiver, or a saint, or someone to feel sorry for. And most of all I tire of the mental strain of working out how to be involved in things, or deciding our family cannot participate in aspects of school, parish and community life and for myself, my workplace. At times I feel socially isolated.

In my ideal world, everyone would be valued for who they are. Those with disabilities or other special needs would be assisted, not excluded. Buildings would be accessible to all. Communities would embrace others in all diversity. There wouldn't be complaints about special treatment because everyone would realise each person has their own particular needs, and part

of community is ensuring everyone's needs are met, not just those of the mainstream.

For me, it's particularly important that faith communities reflect Gospel values. St John's is a welcoming place but I think there's room to build on that. We talk about the poor as if they are only outside the church. That's important, but what about those impoverished who we know, perhaps lacking a sense of care or community?

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When it comes to Caoimhe, you can help. Greet her as you would any other. When there's only space in the middle of rows, move along so we can sit on an end next to her in her wheelchair. Say 'Peace be with you' to her. She will not reply but I believe her heart says it to you. After Mass – talk to her.

Disability shapes not only those affected and those in caregiver roles, but the whole community. With God, we can contour ourselves too, being loving, inclusive and more than we are.