

Celebrating “Holland”

By Brenda Gordon

“Welcome to Holland” is an insightful essay written in 1987 by Emily Perl Kingsley about the experience of having a disabled child. All along you’d dreamed what it would be like to have a beautiful new healthy baby and had planned accordingly. Only the outcome was other than you’d hoped for. Rather like planning that dream trip to Tuscany, only to find that, when the plane landed, you were in another country. You’d read the guidebooks, learnt some Italian phrases, bought clothes suited for the season, only to have your hopes dashed.

meet people you never knew existed. The important thing is, you are not in an evil or dreadful place, just very different from what you’d planned. But after you’ve been there a while, you begin to discover that this new country has its compensations.

I understand exactly how Emily Kingsley must have felt. She’d had a Downs child. I had one with Williams Syndrome, a different genetic condition. The initial disappointment fades with time. You realize that if you spend your life mourning not experiencing “Italy”, you will never be free to enjoy the special things about “Holland”.

“I don’t know anything about Holland”, you protest. “I don’t want to stay!” But stay you must. You have no choice.

procedures for two non-interventionist parents whose two other sons had entered the world so easily. Adrian was delivered at 33½ weeks weighing not quite 1½ kilos and had to be incubated in the neonatal unit. His weight gain was slow, but after five weeks he was allowed to come home. During the first night he developed a strangulated bowel, vomited a stool and needed an operation to correct an inguinal hernia. There was a second hernia operation at six months and a third at 18 months.

“I Carried You”

About that time, because of Adrian’s failure to thrive, I was hospitalized with him so he could be bottle-fed on formula. At this time the paediatrician suggested that Adrian might have Williams Syndrome - a condition we’d never heard of. Armed with discouraging xeroxed photographs of not-very-attractive-looking children, he explained that Adrian’s elfin features, slow growth, and hypercalcaemia were symptomatic of a rare genetic condition, 1 in 7500, which results in retarded physical and intellectual development. The geneticist explained that the condition results



Eddie (left) and Adrian (right)

No Choice

“But I don’t know anything about Holland”, you protest. “I don’t want to stay!” But stay you must. You have no choice. You buy a new guidebook, learn new phrases, and

My third pregnancy, at age 40, came as a shock, as we had not planned to have more children. But my husband and I consoled ourselves that this would be the daughter I always wanted. Then complications introduced a raft of unwanted

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from the deletion of some genes on one of the 7th chromosome pair. She said she would prefer not to make a firm diagnosis until Adrian was at least 2 years old, giving us a faint hope that maybe the experts were wrong. But Adrian couldn't even smile until 9 months old - not a good sign.

That first year was hell for me. It was a time when I put God at arm's length. I remember sitting on the bed shaking one time and saying, I can't do this! The only way to survive was to give it all to God. This was the time described in the lines from *Footprints*:

"My precious child, I love you and would never leave you. During your times of trial and suffering, when you saw only one set of footprints, it was then that I carried you."

God loves all people, but the ones he finds particularly irresistible are those who admit they are people with "special needs" and ask for his help.

He did this in many different ways, and still does. I had a guardian angel in a friend from church who would unexpectedly drop by at critical times. She would hang the washing on the line the way I do it, and she was the only visitor ever to vacuum my house.

We waited until Adrian was three to have his condition confirmed by a diagnostic fluorescence test on his chromosomes. I had well and truly landed in "Holland". He didn't walk until he was nearly four and started school with single-syllable sounds, although you wouldn't guess that now from his verbal self. He is 15, and if you were to meet him you would quickly know him and experience the love and affection that he radiates. And he is an effective evangelist! When he was seven, a teacher's aide sent home the following note:

"Today I came to school with a broken toe and couldn't wear my shoes in class. Adrian was very concerned and said to me, after giving me a big hug, 'Please God, give Rose toe big kiss, make better, Amen.' I was so touched, I thought I would share it with you. Nobody has ever said a prayer for me. It was so cute."

Mind-readers

One characteristic of "Williams people" is that they are mind-readers. Certainly they are empathetic. One of the members of the church I attend told me how one day she went to church feeling quite depressed and as soon as Adrian walked in the door he went to her and gave her a big hug. When my husband invites friends and colleagues home for dinner, Adrian often makes a point of thanking God for the meal and visitors, and usually gets everyone holding hands, generally to the wry amusement of non-Christian guests.

Adrian's best friend at high school, where he is mainstreamed, is a Down's boy called Eddie, who has quite severe speech difficulties, but they complement each other in their respective strengths and deficiencies. They also stick up for each other. They both attend swimming lessons after school with other special-needs friends. We mothers sit on the sidelines and watch, talk, and network with each other.

My husband says Adrian has taught him something important about God - that, just as Adrian as a special-needs child evokes our compassionate response, so people with *spiritual* "special needs", who are trapped in their self-destructive lifestyles, evoke God's concern. In most cases, such people, who started life as innocent children, were corrupted along the way. We all fit into this category to some degree or other, when you think about it.

Fortunately, God understands our condition and how it came about. He

loves all people, but the ones he finds particularly irresistible are those who admit they are people with "special needs" and ask for his help.

In a sense, this world is an incubator for the children of God, a kind of spiritual neonatal unit in which God sees helpless individuals fighting to survive. His heart is captured by our vulnerability. This explains why God is able to love the sinner. He is not put off by the spiritually retarded human condition. Rather, he is drawn to it, so as to alleviate it.

Even though you may not be exactly where you planned, you can still make the most of the trip.

I have been in "Holland" for 15 years. It has become home. Here I have met others whose plans changed like mine and who could share my experience. We have supported one another and some have become good friends. Sometimes I wonder what it would have been like if I had landed in Italy as planned. Would life have been easier? Would it have been rewarding? Would I have learned some of the important lessons I treasure today?

The journey has indeed been challenging, and at times I would (and sometimes still do) protest in frustration and concern. But what is more important is what you make of your journey. Someone wisely said: "The will of God will never take you where the grace of God will not protect you." Even though you may not be exactly where you planned, you can still make the most of the trip.

Brenda Gordon lives in Wellington, with her husband, Dennis, and Adrian.

