

Book review

Michael - A Transforming Presence

by Maureen E Lahiff

Maureen Lahiff lives quite locally to me and although I have not met her, she has connections to our church and it was through these that I came across a copy of her book.

The 'Michael' in the title is Maureen's older son, who was born with Down's syndrome. Maureen and her husband Kerry had two sons - Michael, and his brother, David. Sadly, David developed epilepsy in his late teens, experienced occasional seizures, and at the age of 20 had a severe seizure that resulted in untreatable brain damage. This led to his death within a short space of time.

Seventeen years later, Michael contracted meningitis, from which he never recovered, leaving Maureen and Kerry to face the traumatic decision of turning off life support, once it was obvious that nothing could be done to save his life.

The book talks about their different paths of grief, but it also addresses so much more. It is a mother's reflection on her own faith journey through tragedy, and her reflection on all that Michael taught her, and others, about disability, including living life to the full, spirituality, ethics and theology.

Maureen is very honest about her reactions to the news that her firstborn son had Down's syndrome (or, as she was told by the medical staff, in those days, was a 'Mongol'). She describes how in the weeks after Michael's birth she was too depressed even to cry and experienced many conflicting feelings.

She loved Michael and indeed she totally rejected the suggestion of him being adopted, but she nevertheless struggled to care for

him and indeed found that the only way for them to survive as a family was for her to work (as a nurse) while Michael was cared for by others during the week. She describes honestly her disappointment and her grief for 'the baby she did not have', despite the fact that she had nursed disabled people and trained other nurses about how to care for people with disabilities. (To her credit, Maureen rose to a very senior position in the Royal College of Nursing).

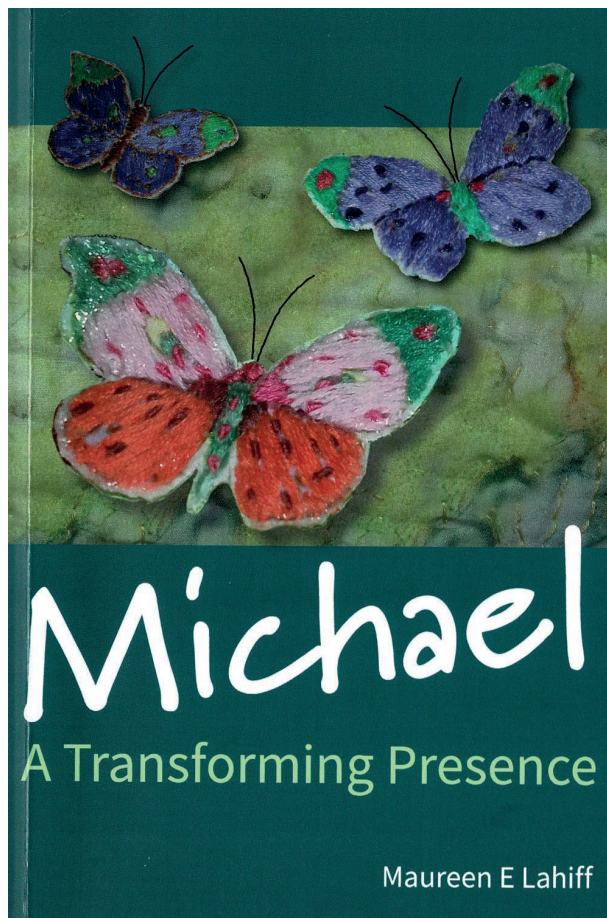
She describes how her views of disability and illness were shaped by her family's historic attitudes, societal values and a medical model with which she was professionally familiar. Family experiences seemed to imply that such things were shameful and to be hidden. Societal values regarding young people seemed to be based on achieving independence, being successful at school, and having a good job. Therefore, realising that Michael's ability to achieve any or all of these would be limited, the implication seemed to be that he would fall below expectations. Being a nurse, Maureen acknowledges that the medical model of 'needing to fix' as opposed to the more socially-minded view of 'what can be done?' influenced her sufficiently to conclude that if fixing cannot happen, then nothing can be done.

She also reflects on the influence of living in a society which is generally time poor, with the pervading

inference that the extra time needed for people with disabilities to perform routine activities, to communicate, to relate, etc., becomes an inconvenience that is not easily accommodated.

Maureen writes with candour about the struggles in her marriage, due in part to the pressures of having a child with disability, the sudden death of David, and the fact that Kerry, her husband, had remained undiagnosed on the autistic spectrum for many years. Kerry and Maureen were, however, married for nearly 50 years, with Kerry suffering from dementia for the last five years of his life.

Much of the book is dedicated to exploring the spiritual journey Maureen undertook, one that was influenced by Michael in the way that he touched the spiritual journey of so many other people too. Maureen had been an active Christian in her youth and then



drifted away, but started to return after Michael's birth, when she and Kerry wanted him to be baptised.

Michael had an incredibly open, unconventional, deep relationship with God. Throughout his life there were times when his lack of inhibition seemed to enable the Holy Spirit to work through him - challenging, comforting and bringing joy to many. He could connect to God and others without the need for many words.

The accounts of how Michael expressed his faith, often in unexpected ways, are amusing, moving and challenging to us all in terms of how we often expect people to conform in church, and what inclusivity really means.

Michael struggled following the death of his brother, but found art therapy as a very helpful way of working through his grief, and a training video of his experiences was made for the Royal College of Nursing.

For the final five years of his life Michael lived in a L'Arche Community in Bognor Regis. After some initial difficulties settling in, the experience of living in a community where there was no sense of 'them and us' between residents and volunteers, and where there existed a willingness for everyone to learn from each other, transformed Michael into a much happier, fulfilled person and took him on a whole new depth of spiritual journeying. One of the L'Arche volunteers, speaking at Michael's funeral, said, 'I was moved more and more by Mike's real and honest style of praying; truly conversational, a direct line to the Lord, a stream of consciousness which was often hard to follow, but always profound - if you really listened to his words, rather than watching the clock, worrying about whether he was over his allotted time or whether he conformed to how he was meant to behave'.

This statement touches upon one of the other issues addressed by Maureen - our theology of disability,

and how as, people of faith, we understand disability. We can look at the stories of Jesus healing people and see disability as being something in and of itself that needs to be fixed, but perhaps we do that in order to make ourselves feel better somehow. Maybe we hope for healing so that those who are healed then conform, so to speak, meaning that our need to change or adapt is lessened. However, Maureen contends that stories of Jesus bringing healing to people are actually so much more about restoring the marginalised, crossing the rules of the day (religious or societal), and thereby enabling those on the edges of society to be included and fulfilled. In the modern world, and within the Church, we should perhaps be addressing the same issues. In his book *Disability: The Inclusive Church Resource*, John M Hull says that 'the biggest problem that people with disabilities face is other people - their lack of sensitivity, obstructions, ignorance and assumptions'.

In the final part of the book, Maureen raises the delicate issue of ethics. We live in a conflicted society, one which promotes care, equality and rights for people with disability yet at the same time facilitates terminations of babies with 'abnormalities'. She does not offer any easy answers, as she realises there aren't any, and with commendable honesty she says that if she had known before his birth that Michael had Down's, she would have had an abortion. She and many others, though, are thankful that she did not!

'Michael - A Transforming Presence' can be purchased by contacting Maureen Lahiff directly at maulahiff@gmail.com

I have been thinking about how we as counsellors and pastoral carers are equipped and trained to work with people with disability, which was probably what sparked my interest in Maureen's story. I have been concentrating on physical disability, but the same issues

apply to all categories of disability - how we adapt our practices, rather than expect people to conform, how we work inclusively, how we better understand the issues that people with disability face, etc.

I have been talking to an organisation called 'spokzpeople' (www.spokzpeople.org.uk) and have found some very helpful information on their website, a link to which can be found on the ACC website. I have also been thinking about setting up a forum within ACC, for counsellors and pastoral carers who work with people with disabilities, where we can share knowledge, experiences, ideas, etc.

I have yet to find any specific training resources on working with disability, and it appears there is very little research taking place into the mental health of people with disabilities, so I wondered if a forum would serve as a means of support, learning and equipping as a shared experience. If you are interested in being part of such a group, please do get in touch via office@acc-uk.org

I know I for one have much to learn from others working in this area as well as from those we counsel and care for.

¹ *Disability: The Inclusive Church Resource*, John M. Hull.

Reviewed by Chris Monckton-Rickett

Chris is a Registered Accredited Counsellor, with over 25 years experience. He and



wife Sue run WINGS (Wholeness In God's Son), providing counselling, retreat leading and training in counselling, pastoral care and prayer ministry and church consultancy.