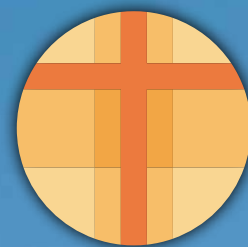


Luke's Journal

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CMDFA
CHRISTIAN MEDICAL
& DENTAL FELLOWSHIP
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The
Theological
Challenge of
Disability

Disarming Disability

Reflections on
Learning from People
Living with Disability

**GOD WORKS
THROUGH
DISABILITY, NOT
JUST HEALING!**

**PARKINSON'S DISEASE:
A DISABILITY OR
A BLESSING?
(OR BOTH?)**

**GOD'S PROVISION
FOR A DOCTOR'S
LONG-TERM ILLNESS
JOURNEY**

**Disability Inclusion
and the World's
Poorest People**

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Disarming Disability

A recent systematic review of the global impact of disability¹, estimates 15% of the world population, or one billion people, live with a disability. This paper identifies a strong link between disability and poverty in low and middle income countries (LMICs) and consequently identifies a gap in the previous millennium development goals to be addressed in the new 2030 Sustainable Development Goals (SDGs).

Disability, including mobility disability, has always assumed the underside position in history. It was not till the mid-1980s that disability studies became a genuine academic pursuit. Scattered interest was evident prior to this. The pioneering work of Dr Paul Brand² with disabled victims of leprosy acted as a model for progress. Forces to improve socio-economic status have always benefited disabled citizens³, but considerable impetus has come in the wake of the International Year of the Disabled in 1981. This has spawned not only health advances but design, technology and social inclusion changes which are truly life-changing for many disabled people. We have seen the rise of the Paralympics and here in Australia, significant social capital is being invested in the National Disability Insurance Scheme. Health and education have made big strides forward on this change wave. People with disability now sit in the Australian Parliament.

In a sense, a thorough Christian response to disability has shadowed the church's response to slavery. The Biblical elements of a comprehensive response to disability have remained undisturbed for almost 2000 years. There have been sporadic limited responses, however the church must bear some shame. Responding to disability has been an enduring 'blind spot'.

That "Now is the Time for Disability", is to be embraced. With the scales



removed from our eyes (and hearts), there are many genuine and imaginative responses to the multimodal suffering of people living with disability.

This edition of *Luke's Journal* explores the long-dormant Biblical mandate to respond imaginatively, in order to enable people living with disability to flourish. We will be inspired by good science, good public policy and the personal stories of individuals who have been able to disarm their disability experience.

The story of 'love coming to town', for disability has faced a long run-up. At the same time, Jesus' own performance review criteria were that "the blind receive sight, the lame walk, those who have leprosy are cured, the deaf hear, the dead are raised and the good news is preached to the poor," (Luke 7:22). Let us, with humility, commit to an ongoing engagement with the 15% of our global population living each day with disability.

The *Luke's Journal* team have commissioned this material as a call to our CMDFA membership and to

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Luke's Journal

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The Theological Challenge of Disability

I was introduced to disability in 2010 when I had an accident that broke my fourth and fifth cervical vertebrae. It was two weeks before my fortieth birthday, and I was on holidays with my wife and teenage sons in Nowra, when we decided to visit a local church that had set up a bicycle and skateboard jump that landed into a pit of foam (like you may see at a gymnasium). I was the type of father who joined in with his children's adventures, but on my first attempt I landed upside down and knew immediately that my life was changed forever. After the arrival of paramedics and an extremely cautious journey out of the pit, I was flown by helicopter to Prince of Wales Hospital in Randwick. From ICU to the spinal unit, I was to spend seven months in hospital, learning to live as a C5 incomplete quadriplegic.

Theodicy

As an academic theologian, I had theoretical answers to the problem of pain, but spinal cord injury (SCI) made the abstract concrete. I had privileged access to theological friends, and over those seven months in hospital we spent countless hours wrestling with theodicy, the formal label which translates as defence of the faith.

CS Lewis famously summarised the problem of pain as follows:

"If God were good, He would wish to make His creatures perfectly happy, and if God were almighty He would be able to do what He wished. But the creatures are not happy. Therefore, God lacks either goodness, or power, or both."

In the years since leaving hospital, I have thought deeply about my response to Lewis' question, as have most Christian healthcare workers dealing with the suffering they see on a daily basis. And while there is no final answer to the problem of pain,

there are ways of thinking that can help us to navigate the issues. Given the restrictions on the length of this article, and at the risk of being a boasting salesman, I refer readers to my book *Crippled Grace* for a deeper analysis. But in sum, a Christian response to the problem of pain will begin by highlighting sin, since endless human misery is a product of the harm we do to one another.

"Why, God, have you caused or allowed my impairment?"

There is a tendency today to explain away sin, and it is true that our bad choices are at least in part a product of our genetic make-up and the environment in which we are raised. We are victims of sin as much as we are perpetrators. But to explain away sin is to refuse to take responsibility for personal and systemic evil, and so to do nothing about it. Depending on how we define it (a topic to which we shall return), disability is a product of the myriad sins of systemic social injustice.

But sin doesn't explain my injury, which was a product of bad luck and the inherent fragility of our skeletal system, just as it says little about babies born with an impairment, or the hardship that attends cancer. Indeed, the cyclical processes of evolution that gave rise to the wonders of human life can be brutal, and to be human is to be born through a mother's pain, to grow and flourish but also to be at risk of illness, disability, countless hardships and, in too-quick time, to die. Just as through this natural cycle God created an awe-inspiring universe and a beautiful earth, so does another answer to the problem of pain assert that God brings good things out of suffering.

There is deep meaning in the greater good argument. My injury has gifted me with surprising benefits, as I have experienced the love, prayer, and generosity of family, friends and the numerous professionals responsible for my care. It is only in the struggles of life that we learn the virtues (such as love, joy, peace, patience, kindness, goodness, faithfulness, gentleness, and self-control – Galatians 5:22) and shape the stories that make us what we are. What would our world look like without the wisdom of doctors, compassion of nurses, support of chaplains, diligence of carers, and so on?

But there is a difference between the assertion that good can come out of pain and evil, and the claim that God causes evil for a greater good. The latter, which has God responsible for sexual abuse and the horror of human warfare, makes of God a monster, unworthy of faith.

A final response suggests that, while there is no complete answer to the question, 'Why, God, have you caused or allowed my impairment?' other than that the wonders of life go hand in hand with its vulnerabilities, we might ask a different question. Rather than "Why?" we might explore the deeper question, "Where are you, God, when I suffer?" The gospel answers that He is with us in our suffering, and promises resurrection.

So fully did Jesus share in our pain that in the garden of Gethsemane he asks God to "take this cup from me," and on the cross cries "My God, my God, why have you forsaken me?" (Mark 15:35). The cross is the sign that God knows our suffering, even our godforsakenness. The cross is a promise that He is with us in and through our hardship, and the resurrection is the promise of new life and the deep joys of faith, hope, and love.

If Jesus is a model for Christian health professionals, it is not in his disciplinary skill. I suspect the medical board would react poorly to a doctor who spat on the ground and rubbed mud in a patient's eyes. It is in the realisation that the underlying call of all health workers is to be truly present with their client, especially at those times when they feel godforsaken.

Models of disability

There is more that might be said along these lines, but by concentrating a theology of disability on theodicy, we assume that the problem of disability is a person's impairment and the functional losses that result from it. This makes some sense in the case of a spinal cord injury, but the ground-breaking insight of the twentieth century disability rights movement was that disability is a social problem.

The medical model of disability, which still predominates in Western culture (especially in our hospital bureaucracies), locates the problem of disability with the individual, in which case its solution is medical intervention. The social model argues that disability is a product of societies that are shaped to exclude non-standard bodies and brains. People with impairments are disabled when the physical environment prevents their participation, such as when buildings are blocked by steps, social events fail to provide translation services to enable communication for people with deafness and blindness, and educational systems are set up to meet the needs of supposedly average students, but not to accommodate people with learning difficulties.

More broadly, disability is a product of a cultural environment that sustains unjust and exclusionary social conditions. Even with the implementation of the NDIS (which

*Professor
Shane Clifton*



is at risk of political interference and bureaucratic bungling), people with disabilities in Australia continue to face disproportionate social disadvantage. They are more likely to be unemployed, to live in poverty or with below average income, and to struggle to find appropriate housing. Given that health is socially determined, they are also more likely to self-report poor health, suffer from mental illness, and be subject to chronic health conditions (unrelated to their impairment). Their life expectancy is lower than the general population. More broadly, people with disabilities experience day-to-day prejudice and paternalism, evidenced

by the fact that they are almost twice as likely to lodge complaints with a Discrimination Commissioner than are persons from any other category (such as sex or race).

Social disadvantage is a cultural problem, but cultures are sustained by the values of prominent individuals and institutions, and religion plays a vital part. Theologians of disability have thus explored ways in which faith can be rallied in the pursuit of justice and social change. Before that is possible, however, religions must face their own culpability.

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Crip theology

Crip theologians, who model their theological advocacy along the lines of feminist theology, have been unafraid to note the ways in which the Church sustains disability prejudice and paternalism, not only by the inaccessibility of their ancient buildings, but by ministries that treat people with disabilities as objects of pity and charity rather than coequal ministers in the priesthood of all believers. When was the last time you heard a sermon from a senior pastor in a wheelchair or with cerebral palsy (presuming they can access the pulpit), or worshipped with a song leader who has an intellectual disability?

The scriptures can and should be a source of disability empowerment. Even so, they are products of an ancient culture, and can be used to sustain prejudice. There are obvious examples, such as the insistence in Leviticus 21:18-23 that a person who is blind, lame, crippled, or a dwarf cannot approach the altar as a priest lest they desecrate the sanctuary. Some Christians are loath to admit that the scriptures are a product of their time, that inspiration is always discerned in the interplay between historical context and divine self-disclosure. The same scriptures that are read with sexist ideology to restrict female ordination and entrench a woman's submission to her husband can be used to keep people with a disability away from the structures of ecclesial power.

In my Pentecostal tradition, the stories of Jesus' healing can make living with a disability difficult, adding the challenge of failed faith to the complications of impairment and prejudice. A person with a permanent disability or terminal illness is the elephant in the room when healing is on the charismatic agenda. Indeed, there is a need for a more careful reading of the Gospels. Jesus' healing ministry was neither absolute nor permanent (he did not heal everybody, and everyone he touched subsequently suffered and died). Further, the purpose of his healing was symbolic, highlighting his unique identity as Messiah, and social, oriented to liberating the poor,

oppressed, sick, and disabled from entrenched social injustice.

For example, Jesus' healing of the woman with the issue of blood (Luke 8:43-48) is not merely the offer of a cure that reveals the power of God. It also confronts millennia of disabling exclusion that made bleeding women unclean. We model our ministry (or healthcare work) on that of Jesus, not by performing healing (although prayer can have miraculous effect, as can the march of medical science), but in our passion for justice, compassion for suffering, and welcome for the excluded.

“Jesus’ healing ministry was neither absolute nor permanent (he did not heal everybody, and everyone he touched subsequently suffered and died).”

Just as artists and theologians have explored the idea of a black Christ, and feminists the female Christ, so can a theology of disability envisage Jesus as disabled. Isaiah 53:2-3, for example, describes the Messiah as having;

“no beauty or majesty to attract us to him, nothing in his appearance that we should desire him. He was despised and rejected by mankind, a man of suffering, and familiar with pain. Like one from whom people hide their faces, he was despised, and we held him in low esteem.”

These are characteristic ways of describing disability, especially the marginalisation and rejection that is central to the social model. That the Gospels elevate the crucified Christ, who after the resurrection retains the scarred holes in his hands, feet and side, is testimony to the divine reversal that is the heart of the gospel; the last shall be first and the seemingly weak will manifest Spirit-filled power.

Conclusion

There is much more to say but no more space to do so. This article is written to medical professionals, so let me finish with the question, what has any of this to do with you? We might respond by exploring the interplay between the medical and social model of disability and, rather than set these two perspectives against one another, keep them in dialectic tension. Disability is both an embodied reality and a social condition. What doctors do matters, but it is not the whole story.

Although I have not touched on it here, the focus of my writing has been the intersection between disability and virtue ethics, and it is my view that a theology of disability invites experts to reflect upon the virtues of character needed, in addition to disciplinary expertise, for effective long-term work with people with disabilities. Since paternalism is at the heart of disablement, experts need to learn the too rarely practised virtue of humility. Qualifications and experience cement expertise, but it is the disabled client who is the real expert in her own body and the challenges of her social location.

Thus, you might consider your job an exchange. You bring an expertise to address a specific issue, and the client brings insight into what it means to live with a vulnerable body in a world that continues to need the justice that lies at the heart of the gospel:

“The Spirit of the Lord is on me, because he has anointed me, to proclaim good news to the poor. He has sent me to proclaim freedom for the prisoners and recovery of sight for the blind, to set the oppressed free, to proclaim the year of the Lord’s favour.” Luke 4:18-19 ●

by Professor Shane Clifton

Shane Clifton is Professor of Theology and Director of Research at Alphacrucis College, and Honorary Associate, Centre for Disability Research and Policy, the Faculty of Health Sciences, the University of Sydney. His recently published book *Crippled Grace: Disability, Virtue Ethics, and the Good Life* (Waco, Texas: Baylor University Press, 2018) is available from Amazon, Baylor University Press, or in Australia through Alphacrucis College (02 8893 9000).



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Disability and the Body of Christ

Like many people, I had never stopped to think about the challenges experienced by people with disability in the church. I didn't really think about the difficulty faced by church members in wheelchairs or walking frames attempting to enter heritage-listed buildings with steep stairs and no ramp. I didn't think about the distress that could be caused by the absence of accessible parking or accessible toilets (formerly called *disabled* parking and *disabled* toilets). I didn't think about the concerns of parents of children with autism and whether their child would be accepted by their peers and included in kids' church. These things were simply not on my radar until disability suddenly became personal. For me, this was in the form of my brother-in-law John.

By the time I married my husband Mark, John was 14 years old. Through my relationship with John and my parents-in-law, I became more aware of the barriers that prevent people with disability being included in society. But while I grew in my general understanding of disability, I did not give any consideration at all to disability in the context of the church. This changed in the year 2000 when a new minister began at the church John and my parents-in-law were attending. While John had been involved for many years with welcoming, handing out church bulletins, as well as making other contributions to Sunday services, when this new minister began at the family's church, he immediately put a stop to all John's serving roles. The belief of the minister was that someone with an intellectual disability doesn't have the capacity to understand the gospel and therefore shouldn't be allowed to be in any up-front position in the church even if that is simply greeting people at the door. While my immediate response was one of

shock, I realised that I had never really considered disability from a theological perspective before. Suddenly, I had a myriad of questions I wanted answered. Was the minister justified in his decision? Is it really impossible for someone with an intellectual disability to understand the gospel? Is there anything in the Bible that can direct believers on how we should treat the people with disability in our midst? And so, what began as a series of theological questions for me, has resulted in, so far, seventeen years of writing and teaching on disability and the Bible.

Although, prior to this incident with John, I had never thought about disability and the church, I quickly became incredibly passionate about working towards the full inclusion of people with disability into church communities. I met with people

that were inaccessible for people with disability. And what I heard – and still hear regularly – from ministers and church members is that people with disability make up only a small percentage of the community, so it is simply not economical to make changes to the physical access of the church building for such a small number of people. “Besides,” I have often been told, “we don't have anyone with a disability in our church so we don't actually need a ramp.” The irony of this seems lost on those who make this suggestion.

There are some flaws in this argument. Firstly, the World Health Organisation estimates that more than one billion people live with disability, approximately 15% of the world's population. Not only this, but research shows that statistically every person on the planet will pass through some

“Is it really impossible for someone with an intellectual disability to understand the gospel? Is there anything in the Bible that can direct believers on how we should treat the people with disability in our midst?”

.....

with disability and their families and carers and heard stories of church communities that lived out Paul's radical image of unity in the body of Christ with all members being valued and included, irrespective of physical or intellectual ability or disability. But what I also heard were stories from families who were asked to leave their children with disability at home on Sundays because their child was considered too disruptive by the congregation. Others with disability shared that they were never able to attend church camps because their church always selected campsites

period of their life with disability. For some people, that disability might be a permanent condition that is apparent from birth. For others, their disability might be acquired during their lifetime as a result of an illness or ageing. For others still, disability might only be temporary following an injury or accident. But, whether that disability is permanent or temporary, evidence indicates that the average person in the western world will spend between **eight and twenty years** of their life with some form of disability. This means that at some point, every human being will

experience what it means to have a disability – either in their own bodies, or in the bodies of their parents, children, siblings or friends. Disability is not restricted to a small percentage of the community. Rather, disability is a constant and inevitable reality of the human experience. And if disability is an inevitable part of the human condition then disability is also going to be an inevitable part of our church communities, whether we are willing to recognise it or not.

In his first letter to the church in Corinth, the Apostle Paul uses the image of a body to describe the members of the church. Paul says that just as in a human body there are different members of the body with different functions, so it is also with the body of Christ. Paul says that while there is enormous diversity among the members of this body too, all members are called to live in unity and are to be given opportunities to use their unique spiritual gifts in service to the body.

Often Paul's descriptions of individual spiritual gifts are interpreted in terms of a person's natural or learned abilities. However, Paul is not talking about natural talents but about the spiritual gifts allocated to one and all in the body of Christ by the Spirit. While sometimes these spiritual gifts might overlap with a person's natural or learned abilities (eg. someone who is a good public speaker might also have the spiritual gift of teaching), we cannot be certain that this is always going to be the case. This means it is impossible for us to discern a person's spiritual gifts based on their physical or intellectual capacity. While we might assume, as the minister in John's church did, that someone with an intellectual disability cannot understand the gospel, the reality is that it is the Spirit who distributes gifts to every member of the body and does so for the common good of the body. How then can any member of the body declare the uselessness or limitations of the gifts God has imparted on another member of the body? Indeed, Paul addresses this very topic in 1 Corinthians 12:21 "The eye cannot say to the hand, "I don't need you!" And the head cannot say to the feet, "I don't need you!" Every member is given spiritual gifts by the Spirit and the



capacity to be able to use those gifts to serve the body, even when those gifts are not immediately apparent to the other members of the body. In fact, Paul says that those members whom we consider "weaker" – whether because of physical or intellectual disability, age, illness, socio-economic status or anything else – are actually "indispensable" for the effective functioning of the body of Christ! It is "God (who) has placed the parts of the body, every one of them, just as he wanted them to be" (12:18)

Earlier in the same passage, Paul says that each one of these spiritual gifts is given as "a manifestation of the Spirit." However, the word "manifestation" here could easily be translated "revelation". The gifts of the spirit thus serve to reveal the Spirit to each and every one of the members of the body. This idea of "revealing" the Spirit is helpful in that it emphasises that through the exercising of spiritual gifts, each member of the body has the capacity to demonstrate, indeed, reveal, something of God's Spirit to others in the body. Whatever a person's physical or intellectual capacity, whatever a person's natural talents, every member of the body has been allocated their own spiritual gifts which they are to utilise in order to reveal the Spirit for the edification of the whole body.

Paul is concerned that the members of the Corinthian church are labelling some of the other members "weaker" than others because they do not possess some of the more apparent 'prestigious' spiritual gifts, such as that

of prophecy or teaching. But whether these members are considered "weaker" because of physical weakness, social powerlessness or because of an apparent lack of wisdom (in relation to the Corinthians' warped ideas of what spiritual wisdom actually looked like), Paul cautions the Corinthian church against such judgements by saying that: "...those parts of the body that seem to be weaker are indispensable." (1 Cor 12:22).

Throughout his letters to the Corinthian church, Paul talks a great deal about weakness. In one sense, Paul talks about weakness as an inevitable part of the human experience and our participation in a fallen world. We all experience limitations in our bodies, the things we wish our bodies could do but cannot. We all experience the effects of ageing and we will all experience the ultimate sign of the fall and human limitation: a physical death. It is only in the fullness of the resurrection that this weakness will be cast off: then our bodies that are "sown in weakness, (will be) raised in power" (1 Cor 15: 43). This is weakness we all jointly participate in, despite appearances that some might be stronger or smarter than others. In this sense, while we all have various abilities and disabilities that make us different, our shared experience of human limitation is what makes us all the same.

But Paul also talks about weakness in 1 Corinthians 12 as that which only

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DISABILITY AND THE BODY OF CHRIST

appears to be weakness. Paul is aware that the Corinthians are judging one another based on a range of different categories – who was wiser, who possessed the greater gifts, who had greater social power – but Paul says the categories that the Corinthians were using to judge one another were completely flawed because this was merely the *appearance* of weakness. Whatever categories we might use to refer to others as weak, as unable, Paul relegates to a mere illusion because those parts that we choose to render weak are actually indispensable for the effective functioning of the body of Christ. Paul challenges us that we cannot judge one another based on outward appearance or physical or intellectual capacity because this is simply not the way God has put the body of Christ together. He has put the members of the body together in the way He wished it, ensuring all members serve and encourage one another as they play their part in the body in the service of Christ.

When we reflect on the message of Christmas, we are reminded that Jesus Himself came bearing all the signs of human weakness. He came in the form of a vulnerable baby, wholly reliant on others for nurture and care. He experienced the limitations of the human body and was as susceptible as any of us to hunger, tiredness and sorrow. Not only this, but while Jesus' followers anticipated a Messiah who would lead a rebellion and fight against their Roman oppressors, Jesus did something wholly unexpected – He died in the shameful way of the cross. The message of Jesus' life and death might have all the appearance of weakness and foolishness. However, this was actually the ultimate demonstration of God's power at work, as it was the means through which we are offered salvation.

While it is easy to judge others based on worldly classifications of power and weakness, ability and disability, the message of Jesus is one of God demonstrating His power in the most unexpected way. Given that this is the upside-down message of the gospel, should not the body of Christ respond

accordingly? Rather than marginalising and excluding those people deemed weak and powerless by our society, Paul says these are people who are indispensable to the body of Christ.

Paul's radical vision of the body of Christ as a place of community and participation for all members emphasises the power of the gospel to unify believers, while simultaneously acknowledging the unique contribution every member brings to the body. Irrespective of intellectual or physical ability or disability, it is God who had placed all the members of the body where he wished them to be "for the common good" (1 Cor 12:7) of the whole body. Rather than judging one another based on worldly standards, let us celebrate and embrace the wonderful diversity God has provided for us as we live in service to Him and in each other as part of the body of Christ.

"Paul challenges us that we cannot judge one another based on outward appearance or physical or intellectual capacity because this is simply not the way God has put the body of Christ together."

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Some tips for helping to include people with disability in church

As stated above, I have met with many people from various church communities and have often heard it said "we don't have anyone with a disability in our church so we don't need to put in a ramp." Not only does this statement overlook the fact that disability comes in a myriad of shapes and sizes (not everyone with a disability requires a ramp), but it overlooks the fact that most churches would already have people with disability as part of their church community but perhaps haven't thought of them in this way. Are there older people with hearing or vision loss in your church? Are there people with mental health issues in your church? Remember, not all disability looks the same!

One of the helpful things churches can do to encourage disability

inclusion is an accessibility audit. There are two types of accessibility audits. Firstly, churches can do an audit of the *physical* accessibility of the church premises. This can be done by an occupational therapist or an organisation that specialises in the accessibility of buildings. In preparation for this physical audit, you can download an accessibility checklist online to help you think through the kinds of access issues an auditor might address. For example, the Western Australian government has a great checklist available at www.disability.wa.gov.au. Search for "Access and Inclusion Resource Kit."

The second kind of audit is one that considers the experiences of people with disability already in your church community. This might include questions about *physical* access, but also questions about how well

the existing church programs are catering for people with disability. Do people feel welcome at bible study groups or on church camp? Do kids with disability feel like they are welcomed and belong in the kids' church program? This audit consists of a questionnaire to all adult members of your church asking them to reflect upon the physical and social access to the church. People can fill in the forms anonymously if they wish, but can also use the opportunity to address concerns they might have about particular elements of access related to their own disability/illness. Many churches have found this process helpful. A good place to start for this kind of audit is with the "All Welcome" Resource available from *Through the Roof* in the UK (this resource costs £5) or readers can contact me on the included email address for a sample questionnaire.

When it comes to including people with disability in churches, we often assume this can be done simply through the addition of an accessible toilet and a ramp to the front door. However, whilst physical access is important, there are many other issues that need to be considered to make churches more disability-friendly. Some simple things to consider are things like the size/style of the font used for PowerPoints and/or church bulletins. In the interest of saving paper, we often like to use small print on A5 handouts. However, this isn't very easy to see for many of us, let alone people with low vision. Consider making large print copies available for those who need it. Vision Australia have a fantastic Document Accessibility Toolbar which can be downloaded as an add-in for Microsoft Word so that it makes it quicker and easier to ensure you create accessible documents. This is free to download and is available at <https://www.visionaustralia.org/dat>.

Churches should likewise consider large print Bibles for church members with low vision. The Bible Society as well as other Christian retailers like Koorong and Word all have a range of large print Bibles available.

Although PowerPoint doesn't use a paper format, often people using PowerPoint slides with their sermon illustrations or song lyrics use a small font. The World Blind Union have some great guidelines on the best fonts, font size, and colours to use on PowerPoint slides that increase readability, not just for people with low vision, but for all people. These guidelines can be found at World Blind Union website (www.worldblindunion.org), searching for "Powerpoint Guidelines."

In terms of readability, churches should also consider whether their church website is compatible with various forms of assistive technologies used for people with disabilities, especially for those with low vision. Again, Vision Australia prove to be an excellent resource in this respect and even provide a Web Accessibility Audit to ensure that websites are accessible and comply with the requirements of



the Disability Discrimination Act. This information can be found on the Vision Australia website at <https://www.visionaustralia.org/services/digital-access/services/testing>.

The numbers of children diagnosed with autism each year in Australia is on the increase. Many families of children with disability find church very difficult for a number of reasons. I have heard it said many times that when parents spend all week being their child's advocate at school, at medical appointments, with the NDIS and so on, that it feels like too much to bear to have to advocate at church as well. Many parents of children with disability simply wish for their child to be included and accepted without having to convince people at church that this is necessary.

Not all children with disability are the same, just as not all children in general are the same. However, there are some general tips you can employ in kids'

church programs in order to be more inclusive. The first thing is to increase the visuals. One particularly helpful visual is a timetable of what will be happening at kids' church. A visual timetable gives children a reminder of what is happening and in what order. For some children, this creates a feeling of comfort as they know what to expect out of the session. Other visuals can also be employed throughout the Bible lesson, music, and other activities to help children stay engaged.

In the same way, increasing the sensory experience of kids' church can help children to learn and stay engaged throughout the lesson. Kids' church leaders should consider ways they can make their sessions more sensorially diverse. Rather than just having the children listen to a story, why not act it out or have props to coincide with the Bible story. What did the sand feel like that Jesus wandered through in the desert? What did the fish and the bread smell like at the feeding of the 5000? Using different sensory experiences not only helps children to engage better with the content but can also help them remember the content as the leader helps to create an experience and not just an oral telling of a story.

For more information and helpful tips on including people with disability in church communities, contact CBM Australia and their Luke 14 program at <https://www.cbm.org.au/get-involved/church/> to find out about hosting a Luke 14 seminar at your church. ●

by Dr Louise Gosbell

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The Lame will Leap for Joy!

I am an inquisitive person. I grew up with a dad who had a mobility disability. He contracted poliomyelitis as a four year old. Consequently I have been intrigued by the claim of Jesus that "The lame walk". Indeed Jesus made this observation as a performance indicator of his status as God's messiah (Luke 7:22).

My father, John Mercer, was born in 1927 and polio seriously impacted his childhood and family life. The neuromuscular impact for him was quite severe, and he required multiple surgeries on his feet as the complication of talipes equinovarus set in. Disability, pain and long, lonely days in hospital interrupted his childhood. His mum, Elizabeth, was heroic in helping dad and raising seven other siblings.

Mobility disability is associated with many downstream health consequences. A Canadian study¹ demonstrated that 11.5% of the population is affected by mobility impairments. These are people at high risk of falls and fall-related injury. They also experience greater rates of obesity, diabetes and cardiovascular disease and decreased independence in activities of daily living.

I don't think my father knew Jesus had been a carpenter when he made a commitment to Christ in 1947. His grandfather took a special interest in his life course and, apart from teaching carpentry skills, felt dad might do better in the clothing industry. It was at his first job making suits that the witness of two Christian co-workers led the way to Christ. Becoming the first Christian in this immigrant Scottish family was a recreating event for Dad. He became open to the possibility of full-time Christian service and enrolled in study at the Melbourne Bible Institute. Through Sunday School duties at a local Presbyterian Church, he met my mother Phyllis. They grew into a loving partnership for mission.

My father was uncertain of his potential for mission service with his mobility disability. However, his training prepared him to expect God to guide, through the reading of scripture. When he read the Psalms² a conviction came on his life. "His (God's) pleasure is not in the strength of a horse, nor his delight in the legs of a man." Polio was not an excuse to refuse to surrender to God's calling. Theologian Soren Kierkegaard offers a further reframe. He says "With the help of the thorn in my foot, I spring higher than anyone with sound feet."³

Dad spent ten years working as a pioneer builder and church planter in East Arnhem Land. At one point his leg irons were lost overboard when a large wave capsized his canoe. In the end, his legs began to suffer from the impact of milling timber, building and walking on sandy soil. He returned to the south and trained to become a Presbyterian Minister. His home design for a culturally-sensitive dwelling for Indigenous Australians was adopted by the Northern Territory Housing Department. Dad was a loyal, dedicated, determined and compassionate man, who, with my mother's support, walked the talk of the gospel in this missional context.

In 1960, CMS invited Festo Kivengere, a renowned Ugandan Christian, to speak the gospel into these communities. As a five year old boy, I responded with a group of Indigenous people. I consider this to have been a special part of my own life story. As I became a blood brother in Christ with these Indigenous Australians, it was in considerable part to my father's surrender of his lame legs and heart to Jesus.

I have my own history of mobility challenges. The most significant event occurred in 2009 when I injured my left foot in a ride-on mower accident. This has meant I live with a mild mobility

challenge. The background to my inquisitiveness is now revealed.

A career in general practice has also taught me many things about disability – particularly mobility disability. I have learnt some lessons about compassion, respect, advocacy and healing in this context. My own story is mirrored by almost a lifetime of hearing God's story. The Old and New Testaments can be recognised as the way God has shared the divine story of the "Life of God" in the context of a sweep of ancient human history. So I began to explore the story of mobility disability in the Bible. How might this inform the claim of Jesus that the "lame walk?" I soon encountered a considerable amount of material – it starts with God desiring to walk with us.

In the Genesis creation story⁴ we encounter a game of hide and seek. The first humans, Adam and Eve have made a choice which has left them with a sense of shame. Even now, the thought of walking with God in the cool of the evening presses buttons deep within our moulded clay. Eating the forbidden fruit of the "tree of the knowledge of the good and evil" was overstepping the mark. We could say the trust that allowed God to meander with us, with humanity, now breaks down. A crippling shame overcomes human consciousness. A hard road, a hard way of sin was born in this story. The story is also saying this is the creator God who simply enjoys a stroll with his image bearers. A 'walking' God will always be in the back of our mind.

East of Eden, the Biblical story maintains a keen interest in "walking with God". Indeed, in a call to faithfulness from Israel, God puts his cards on the table with Moses: Israel's obedience will restore the "evening walks". "I will walk among you and be your God, and you will be my people"⁵. God yearns for Israel to "walk in my ways" (Zeph 3:7) and often people do. So in Ps 116:8-9 the poet says,

"For you have delivered... my feet from stumbling. I walk before the Lord in the Land of the Living" and, more so in Ps 119:45, "I will walk about in freedom for I have sought out your precepts."

Old Testament writers mock idols because they "have feet but cannot walk" (Ps 115:17), while affirming "the Lord upholds those who fall and lifts up all who are bowed down" (Ps 145:14). They also recognise that Satan "walks to and fro on the earth" (Job 1:7).

It is but a small step from walking to lameness. The brief but rich imagery of walking with God that I have presented takes another turn when mobility is compromised. Life starts without mobility – we need to crawl before we walk – and life often ends with disability from sarcopenia of aging, or chronic disease of neurological, musculoskeletal or vascular system origin. Along the way birth defects, accidents, infections and so on, can all impact on mobility.

In the Biblical corpus, the Jewish people remember their primary story of lameness by not "eating the thigh muscle that is on the hip socket" (Gen 32:32). It is the story of Jacob. Jacob has chosen to return to the land God gave his grandfather Abraham. He has been away finding a wife and building his wealth. In a strange encounter at night, we find Jacob wrestling with God who breaks the stalemate by dislocating a hip. He is left to limp away and to reunite with his estranged brother Esau, but not before seeking a blessing. Jacob seems to specialise in finding the advantage in any context. The reply is unexpected, "You shall no longer be called Jacob, but Israel, for you have striven with God and humans and prevailed"⁶. While little is subsequently made of Jacob's limp, it does seem relevant to our question about the "lame walking". It also suggests this question: Is some sort of wrestle with God a project for all of us? Is lameness a metaphor for the struggle, the disconnect, between all humanity and God? I will return to this story.

The second entry is much less subtle. In Leviticus 21:18 we read no lame priest can serve before the "holy of holies" and further in Deuteronomy 15:21, God's people were to avoid sacrificing lame animals in worship rituals. In Jesus' day,



this purity-based religion held sway and is at the basis of many of the conflicts between Jesus and the authorities. Indeed, the Essenes of Dead Sea Scroll fame lived in community with essentially a priestly lifestyle and insisted vigorously that the "crippled and lame" were to be excluded from God's kingdom. This was reinforced by the prophet Malachi, who rails against the practice of substituting lame or blemished animals at temple sacrifices.

The story of David's kindness to Jonathan's crippled son, Mephibosheth, introduces themes of compassion, loyalty and dignity.⁷ The story takes a turn toward belittling prejudice (2 Samuel 5:1-10). Suffering is a theme taken up in Judges 1:1-7 and Job (Job 13:27-28). Here the story integrates with one of the Bible's strong "story lines" – that God is on-the-side of the poor, the weak the marginalised and that God chooses to suffer in solidarity with such suffering.⁸

The last Old Testament focus on lameness comes from the prophets who picked up on this image as a way of describing the restoration they imagined in the return of the people of God from exile back to the Promised Land.

The prophetic imagination captures 'exile' in metaphors such as lameness, blindness and muteness. It may be that a long journey through wilderness areas is harsh on the feet of these travellers.⁹ The prophet Isaiah sends words full of hope: "The lame shall leap like a deer and the mute tongue shout for joy" (Isaiah 35:6). The prophet shares a vision of a highway

of holiness laid out by God to bring them home. Here are kingdom echoes strongly synergistic with the ministry of Jesus. With Jesus, the lame walk. With Jesus, the kingdom of God is among us.

Imagination is an aspect of hope. A hope that the lame will walk. In the introduction to the classic Australian novel *I Can Jump Puddles*¹⁰, Alan Marshall shares the story of his childhood. It is more than the story of a crippled boy. As Marshall observes, "the truth it seeks to establish can only be revealed with the help of imagination."

Professor Robert Garland¹¹ writes with authority about daily life in the ancient world. He makes the following points:

1. Around 10% of the population in the ancient world were disabled. In addition to congenital disability, illness or injury often led to permanent disability and life was hazardous. In one study of a cemetery in Southern Italy, 56% of skeletons revealed bony pathology.
2. In Greek and Roman religious cult practice, all priests had to be healthy and not deformed. In many contexts, disabled people could not enter temples.
3. Work options for the disabled were limited, so life was precarious. In Sparta, disabled children were left outside the city to die. Life expectancy definitely was limited for the lame.

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THE LAME WILL LEAP FOR JOY!

4. Communities mostly regarded a disabled person as a bad omen, and if problems did arise, a disabled person was likely to be scapegoated.
5. In the Iliad, the Greek Iron God Hephaestus, who had a limp, captures the popular sentiment about mobility disability in the classic age, when he expresses the wish to “never have been born.”
6. Of some interest to Jesus’ claim, “the lame walk,” is that Caesar Augustus walked with a limp. Both Greek and Roman art showcased the perfect human form. Augustus was represented in such a way, despite his disability.

Theologian Joel Green¹² describes Jesus’ actions in Luke 7 as a “festival of salvation.” So let us turn to the New Testament witness to the lame walking.

The Gospel biographies of Jesus’ life, tell us he healed people with “many and various diseases.”¹³ Mark offers two specific stories. In Chapter 2: 1-12 he tells of friends in Capernaum letting their paralysed companion down through a hastily created hole in the roof of a house. Jesus has been teaching to a ‘full house’ in his Galilean home town.

The healing of this man under these chaotic circumstances highlights a number of issues. The general crowd are awestruck and give praise to God. Both excellent responses. The “teachers of the law” were also present. They were trying to see where Jesus fitted into their theological system. Linking this healing to Jesus’ claim to also have the power to forgive sins, seemed an offensive leap of faith. Jesus challenges their resistant body language.

Mark’s second story invites a brief attention.¹⁴ It continues the drama between Jesus and the teachers of the law. This time a synagogue leader is begging for Jesus to heal his very sick twelve year old daughter. Jesus takes his time getting to Jairus’ home. They are told the girl has died. Creating some privacy for the parents and his disciples, Jesus commands the lifeless child to “get up”. We are told that immediately:

“the girl stood up and walked around.” Healing for Jesus is never a circus trick. This is sensitive, person-centred transformation.

Matthew and Luke both tell the story of Jesus responding to the disciples of John the Baptist when they seek clarification of his status as “Messiah”. Matthew 11:5 and Luke 7:22 both record the same response: “the blind receive sight, the lame walk; those who have leprosy are cured, the deaf hear, the dead are raised and the good news is preached to the poor. Blessed is the man / woman who does not fall away on account of me.” We can recognise a backdrop to this announcement: “The time has come; the kingdom of God is near. Repent and believe the good news.”¹⁵ Jesus’ message and activity was beginning to disturb everyone’s worldview. Matthew repeats this summary of the ministry of Jesus at two other points in his text.¹⁶ In the middle of a large crowd outside Besida, Matthew focuses on Jesus’ compassion as: “the crippled are made well and the lame walk.”¹⁷ Jesus then feeds 4000 people.

Matthew then resets this scene in the temple. When the blind and lame are brought to him to be healed, the children are so excited they sing for joy: “Hosanna to the Son of David!”¹⁸ This time the chief priests join the teachers of the law to express their indignation. Matthew is inviting his readers to walk a mile in Jesus’ shoes. This is no easy walk in the park; the gospel contains no lame excuses. It is God’s call in Jesus to a lover’s leap.

Conflict again is a focus of John’s story at the Sheep’s Gate Pool. It is a not-so-good news story. The text follows:

“Here a great number of disabled people used to lie – the blind, the lame, the paralysed. One who was there had been invalid for thirty-eight years. When Jesus saw him lying there and learned that he had been in this condition for a long time, he asked him, ‘Do you want to get well?’

‘Sir,’ the invalid replied, ‘I have no one to help me into the pool when the water

is stirred. While I am trying to get in, someone goes down ahead of me.’

Then Jesus said to him, ‘Get up! Pick up your mat and walk.’ At once the man was cured; he picked up his mat and walked.”¹⁹ In this story, there is no joy, no transformation; only a lonely broken man who doesn’t “comprehend” his healing, and a group of rigid fundamentalists who justify giving Jesus a hard time because of his Sabbath compassion.

The paired books of Luke and Acts are a rich source of story material. As Joel Green²⁰ again notes, Luke “repeatedly highlights physiological indications and their resolution, as well as psychosocial, pneumatic and cosmic aspects of the cause, experience and healing of illness.”

In our key text in Luke 7, we note that Jesus’ reply to John’s disciples has a missionary concern. Miracles were associated with the Messiah in Judaism. The answer given here is soft and somewhat evasive. The highlight is on “good news.” Jesus is recorded as using the words, “Give as freely as you have received.” (Matt 10:8). These words are a synonym for grace and Luke uses them seven times in Luke – Acts, and then Paul sixteen times in his writing. The words “seen and heard” or “report” are also very important for Luke as he uses them twenty-six times. He wants readers to enter the world of a lame person who is healed and walks, to share in their everyday story!

A clue to Luke’s interest starts in his birth narrative. He relates Elizabeth sharing an insight with Mary: “As soon as the sound of your greeting reached my ears, the baby in my womb leaped for joy.”²¹ While Luke connects with some of the stories in Matthew, he has a broader literary agenda. An example is the story in Luke 13 of the “bent woman.” For eighteen years she faithfully attended the local synagogue. Her restricted mobility catches Jesus’ eye in two ways. This story doesn’t include friends; it leads us to an isolated, disabled woman who faithfully worships God. Jesus lays his hands on her as he speaks words of healing. As she straightens, she is praising God! An indignant official rushes towards them as Jesus again has healed on the Sabbath

Day. Suffering for eighteen years is long enough for the love of God, and Jesus makes his case in the strongest terms. The people, we are told, were delighted.

Our “festival of salvation” is in full swing in the parable of The Great Banquet.²² Jesus has just put out the challenge to anyone capable of funding a banquet to intentionally invite the cripple, the lame, the blind, etc. (Luke 14:13). He then tells a parable where all the movers and shakers in the community have been invited to a great banquet. A humiliating snub evolves in the story, and so the host sends out servants to invite others: “Go out quickly into the streets and alleys of the town and bring in the crippled, the poor, the lame, and the blind.” When some places remain unfilled, the servants are sent to recruit on the highways and byways.

The “feast of the kingdom of God” is wide open to the lame, the poor, and the outsiders. It seems the “good news” is “bad news” for the proud and powerful elite in society.²³ There are many textual insights to be gained by exploring all these healing stories in depth.²⁴

In the ongoing story of the resurrected Jesus in the book of Acts, Luke wants to demonstrate there is no momentum swing. Indeed, Peter and John are positively enthusiastic for the name of Jesus. Without silver or gold they offer to help a crippled beggar: “in the name of Jesus Christ of Nazareth, walk,” (Acts 3-4:31), they call out. An extended narrative unfolds. The dramatic healing of a congenitally lame forty year old man near the Beautiful Gate of the temple, grabbed the attention of a crowd. To see this man “walking and leaping and praising God”, surely meant that the Kingdom of God was among the people. Peter’s confidence in the resurrected Jesus, bolstered by this dancing cripple, the jubilant crowd and his friend John at his side, makes him bold. He is a witness to the truth of Jesus. The enthusiasm is briefly dented by a period of deprivation of liberty as he and John are quizzed before the Sanhedrin, the Jewish Supreme Court.

It is impossible to find a negative in the healing of a man crippled from birth and known to all as a temple beggar. Peter

absorbs all the threats and continues to speak out boldly as the story ends with the comment: “They were all filled (disciples) with the Holy Spirit and spoke the word of God boldly.” This material from Luke, allows us to understand clearly that “the lame will leap for joy!”

The book of Acts gives the impression that healing was a regular feature for the new, vibrant Jesus moment.²⁵ So it is not surprising that Luke has two more stories to finish this “narrative vision of the lame walking”. In Acts 8:4-7, we follow the apostle Philip into Samaria where “many paralytics and cripples were healed. So there was great joy in that city.” You can guess where Luke goes next. We are placed on the bandwagon with Paul and Barnabas, and at Lystra²⁶ they meet another man who was lame from birth. In the middle of his speech, Paul recognised he had the: “faith to be healed,” so he called out, “stand up on your feet!” You guessed it again! “The man jumped up and began to walk!” There is a fine line between pleasure and pain. This excited crowd wanted to worship the two missionaries as the Greek Gods – Hermes and Zeus.²⁷ In the confusion which followed, sentiment changed and Paul was stoned to within an inch of his life.

We have followed the theme of mobility disability in ‘God’s story’. I will make some summary observations before reaching an answer to the question, “What did Jesus mean when he said “The lame walk?”

1. Mobility disability is a significant source of comprehensive suffering in our world. It can impact across the life cycle.
2. The causes of mobility disability are many, from genetic disorders, injuries, illness and the brutal acts of other humans. Injustice is ever present with disability.
3. The biblical narrative responds in many ways. The love of God identifies with and reaches out to people living with all disability including mobility disability. God’s people are called to compassion, respect and to bring healing to such people in the name of Jesus. There is a role for advocacy

and sustaining hope. The background to the whole narrative is a God who desires to “walk with humanity in the cool of the evening”.

4. We live in a generation when the dignity of people with disability has improved significantly. To be disabled is never an easy way. However, the medical therapies, technology, design, improvements and change in social attitudes are evidence of significant healing. This is “now” a sign of the Kingdom and we continue to look forward with hope to the “not yet.” A not yet where tears and sorrow will be no more.²⁸
5. Within the scripture stories, we have also found some harsh realities. There is a religion of purity, which rejects the imperfections of mobility disability. From this source, some refuse compassion. They awkwardly withdraw. A group of contemporary theologians have cast Jesus as an advocate of purity-based religion.²⁹ They argue his focus on healing the sick and disabled was to reinstate their access to the Kingdom of God. This view has a sharply apocalyptic focus. By healing the disabled, Jesus was restoring their right of access to a purity-based vision of the kingdom. I am not convinced.
6. The theme of the Kingdom of God³⁰ is a thick, rich part of the narrative. I would argue that the biblical material we have surveyed calls us beyond a purity-based vision. It is not the self-accomplished righteousness of religious elites that Jesus addresses with his “good news.” The Servant King comes among us. The poor, the harassed, the disabled, all excluded from temple-based purity worship are invited simply to “follow me.” In the fraternity of Jesus there is acceptance, healing, reconciliation and restored dignity. In Jesus we discover we are all in exile from the love of God. The good news of the kingdom is that God finds us in Jesus, and as we repent, as we reorientate to the great love of God, we return home. To heal the lame, indeed

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becomes a sign of the festival of salvation.

The gospels may start with Jesus and his Jewish community, but the joy and freedom of the gospel escapes to embrace the whole world. Luke's stories not only include the poor, the lame and the blind, but the stranger gathered from the highways of the world. Luke makes this "Blind Freddie" clear, with stories of healing after Pentecost in the Jerusalem temple, in Samaria and then in the Gentile world. Here, the new Christian movement brings healing to the lame "in the name of Jesus and the power of the holy spirit." It is a healing irrespective of any prior covenant with the people of Israel. In these three stories, Luke invites us to recognise a global reach of the gospel of Jesus, and a power available for miraculous healing.

These are stories which invite all who follow Jesus to present our feet; healthy and lame as living sacrifices³¹; as feet swift and beautiful for God's purposes.³²

These six summary points bring a substantial dimension of meaning to the phrase "The lame walk!" However I remained unsatisfied. This changed when I discovered the work of Kenneth Bailey in his book *Jacob the Prodigal*.³³ It is with Bailey we can return to the primary Biblical story of lameness, the story of Jacob.

Bailey had become convinced through an extensive immersion in Middle Eastern culture that the parable of the prodigal son is the epicentre of Jesus' understanding of the gospel. In telling this parable, Jesus was taking his place as a Theologian, using the motif of the story of a father and two sons to rework the story of Jacob and Esau.

Bailey had studied the stories in Luke 15 for many years. His meticulous attention to the cultural nuances of these stories had not satisfied him. A footnote about a similarity between the parable and the Jacob-Esau saga by N. T. Wright, was enough to move Bailey's enquiry on. He discovered 51 similarities.

The reworking of Old Testament stories is an important rabbinic theological skill. Bailey discovered four other 'rewrites' of this story which flows from Genesis 27 through to 36:8. The first attempt is contained in the apocryphal book of Jubilees. Philo of Alexandria, a contemporary of Jesus, undertakes this task, as well as Josephus and finally another version is attempted in a work entitled 'Genesis Rabbah'. Bailey's thesis is that in responding to the Pharisees and teachers of the law (Luke 15:2); Jesus takes on the challenge of reworking this saga. Bailey argues that there are two basic ways to do theology. "The first is by using concepts and the second via story and metaphor." Hebrews 11:21 pictures Jacob leaning on his staff, presumably because of his lameness, as he blesses his sons. No doubt Jacob would have been an active listener to Jesus' new story, if he were in the audience. It is of no small significance that Jesus so powerfully reworks the Jacob saga.

For Bailey, an inept oriental patriarch in Isaac is replaced by a compassionate father and his costly love – a love that includes the tender compassion of a mother. Both sons deeply offend the father, but their offence in no way lessens his love and faithfulness to them. The father in the parable evolves into a symbol for Jesus. In Jesus' hands the parable is a story of God's love finding both a lost individual and a 'lost' people.

The return from exile captured into the symbol of 'the lame leaping' must surely be an invitation to individuals and to the whole community. Lame Jacob is both an individual but through his wrestling encounter receives the name for the whole nation of Israel. It is only the deep love of God which can find us in the wilderness of exile, it is a love which finds Israel "leaning on his stick" and at the same time is a love to Samaritans, gentiles and the whole world beyond. It is a love that initiates a festival of salvation for all of us who live as 'lame', in exile from God, so that we can leap for joy!

Conclusion

The story of our time is one that includes major improvements in the life of people with mobility disability. At an individual level, many of us will have a story of

mobility disability as lived experience. A burden of suffering sits like a shadow around mobility disability. As Christians, we have discovered the story of God's grace to enter our stories. God's story contains the dream of compassion and justice for all disabled humanity. It is a story of healing that continues prayerfully 'in the name of Jesus'. God's story also reminds us we have chosen exile in the place of 'walking with God in the cool of the evening'. We all need to be found by the deep love of Jesus. Then like Jacob, and all Israel, we can throw away our sticks and leap with joy. ●

by Dr Paul Mercer

Paul is editor of *Luke's Journal*. Theology on Tap, Brisbane. This article is reworked from a paper presented at Theology-on-Tap in Brisbane, August 2017.



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Reflections on Learning from People Living with Disability

Recently I asked a question of a friend of mine who lives with disability about what his church would lose if he wasn't there. It was part of a panel discussion on disability and the church. His answer was simply, "me". The audience was stunned by the power and simplicity of his answer, as was I. Looking back, I have found myself regularly surprised by the things I have learned from my relationships with people with disability. To my cost, I worked in the disability area for some years before I learned that I was learning.

Jean Vanier writes, "From the beginning, in 1964, L'Arche¹ has been truly a learning experience for me. It has brought me into the world of simple relationships, of fun and laughter. It has brought me back into my body, because people with disabilities do not delight in the intellectual or abstract conversation."² This statement holds true for me also. My first contact with people with an intellectual disability was as a volunteer at the age of 25 in Canberra. I was newly married and yet very immature. I was asked by the disability organisation to drive a group of people for a Saturday picnic once every two weeks but regularly rang in to cancel because I just didn't feel like it. As an unbeliever at that point, I was surprised and somewhat confused at the generous welcome I received from this group of about eight adults when I did turn up. They didn't seem to hold my unreliability against me but just enjoyed going for a picnic when I could be bothered picking them up. Looking back a few years later, I realised that God had spoken to my insecure, broken self at that point and demonstrated the nature of grace and love. My background had not led me to expect that at all!

This experience finally led me into employment in that disability organisation. Jenny, my wife, and I realised that this was where I was meant to be and decided to make the change

before we became too dependent on my much higher public service income. God was teaching us about trust even before we knew him. Within a year of starting in this work, I met Jesus and became a follower. That is a simple statement that leaves out a lot of detail and the impact of spending my weekdays with people with an intellectual disability was profound. As a person who had always felt the need to perform for approval (which didn't come anyway), I found myself in relationships that were unconditional without any deception. If one of the people with whom I worked was upset with me, I knew it straight away and then it was over. I met parents whose commitment to their sons and daughters was total and sacrificial.

"They have taught me that deep relationships take time, listening carefully, paying attention to the health of relationships and giving priority to people and not things."
.....

I have also slowly discovered who I really am and realised that I can't really hide that truth. Henri Nouwen writes that he discovered in living with people with intellectual disability in a L'Arche community, Daybreak, his own disabilities, "I could be close to people in pain because somehow they revealed my pain to me."³ I found that my need for love and acceptance became obvious to me and to others and that was really what led me to Jesus. My confession is that this took a number of years to register. For a long time I felt that I was the giver, the one with the power and the resources, and that the people with whom I worked were the recipients of what I gave. I know that I missed a lot because of that attitude.

I had the enormous privilege to be awarded a Churchill Fellowship in 1983 and spent thirteen weeks learning about the best approaches to training staff working with people with disability and more. During that time, I spent time with one of the most influential people in my life, Dr Wolf Wolfensberger. His work dug deep into the way in which people who are disadvantaged in some way in our society are devalued by the way in which they are treated, including by the services that are there to assist.⁴ It was during this time that it became clear to me that, not only was I party to devaluing practices in my work, but also that I personally had a dehumanising attitude towards the people with whom I worked. That is, that I hadn't been seeing them as an equal being made in the image of God. That was devastating for me, as I had always thought of myself as a kind person who cared about others. I learned the power of repentance in that period of my life.

For the next 35 years, I have been learning almost every day from those who I thought I was there to help in a 'one-way' fashion. John Swinton refers to "timefulness, slowness, gentleness, love, patience, non-anxious presence, Sabbath"⁵ as desirable characteristics of the process of discipleship. He points out the parallels of developing a relationship with a person who has a slower pace than the rest of the world and developing a relationship with Jesus. Both processes share those characteristics. As a person who has absorbed the stressful ways of our society, the people in my life who live with disabilities that cause that slowness are my greatest mentors. That includes people with an intellectual disability as well as those whose physical disability mean things take time, including listening. They have taught me that deep relationships take time, listening carefully, paying attention to the health of relationships and giving priority to people and not things. That applies to

continued page 37.

Compassionate Christian Healthcare

Ask any patient what they want in a healthcare provider, and “compassion” is likely to be one of their priorities.^{1,2} Yet compassion is too frequently seen as being less important than other aspects of care. In recent years there has been a shift towards attempting to perform medicine *with* patients rather than doing it *to* them, a concept known as “patient-centred care”³. While I applaud this, I also see the importance of not losing the healthcare provider’s humanity and autonomy. I see extraordinary potential for blending the best of evidence-based medicine with real patient-centeredness.

This article will discuss what compassion is, and whether it is something worth teaching healthcare students.

What is compassion?

The word is derived from Latin: *com* = “with/alongside” and *passio* = “suffering”.

Therefore, compassion means to suffer with someone – it is an active, as well as an emotional, process.

A definition widely accepted in research is:

the sensitivity shown in order to understand another person’s suffering, combined with a willingness to help and to promote the wellbeing of that person, in order to find a solution to their situation. 4

I believe this is compatible with Christian understanding as well as other worldviews.

My interest in this topic started a few years ago when teaching students about carers (see my blogpost⁵ about this). Students often became very

emotional when they were debriefing about the issues that carers face. Our team researched the empathy of our students, hoping that we were helping to increase their empathy through teaching. Through this research, we discovered that some students weren’t able to cope with the challenges of hearing the stories about carers, and showed a significant drop in their empathy. In other words, they found the reality of what carers face too painful, and they coped with this by emotionally withdrawing. This will be no surprise to anyone who has worked in a clinical setting and seen the way that colleagues depersonalise patients, become cynical, turn to drugs and alcohol, etc..

“...we discovered that some students weren’t able to cope with the challenges of hearing the stories about carers, and showed a significant drop in their empathy.”
.....

So perhaps the solution to this is to teach students how to be more empathetic? There is certainly good evidence that you can teach people how to be empathetic – or at least, how to measure higher on empathy scales! My concern with this is that teaching students how to be more empathetic may actually be teaching students to cover up their true feelings, and simply put on an empathetic act. All that we would be achieving would be the appearance of empathy.

This conundrum is made less vexatious by teaching compassion rather than empathy. There is an important difference between the two:

compassion is taking the empathy that we feel regarding a patient’s suffering and being able to do something about it. Remember that compassion has an active, not just affective, component.

Teaching compassion to healthcare students

If we feel pain, it is very normal to withdraw from it, or to try to shut it out – and this includes emotional pain. Feeling overwhelming empathy for our patients is unhelpful unless we can do something with that empathy: this is what compassion is.

I believe there are several reasons to teach compassion to healthcare students:

Compassion is central to avoiding burnout.

It is no coincidence that empathy declines during the same time as burnout increases – in the early years of clinical practice. When you are burning out, your ability to relate to another’s pain diminishes. For many years the prevailing approach to empathy was to maintain a ‘clinical detachment’. There could be a number of reasons for this approach, all of which would be speculation on my part. Maybe it was because senior doctors had hoped that remaining detached would enable them to make better clinical decisions; possibly it was a self-protective mechanism; perhaps it was simply because they had come close to burnout themselves and remaining detached was their unconscious survival mechanism. Whatever the reasons, we have often been taught to disengage from feelings, back away from them, and ignore them – yet these are all unhealthy coping mechanisms. And they are not the way that Christ deals with us.

It is interesting to note that when empathy moves someone into

compassionate practice they do not tend to find this a draining experience - in fact they experience LESS burnout. So, rather than disconnecting from feelings to avoid burnout, we should be learning to act on those feelings in a helpful and positive way⁶ – this is a far more effective (and Christ-like) approach.

Compassion benefits patients

During my training I was socialised to 'not feel' – there was a belief that "emotions cloud your reasoning" and therefore would impair patient care. We were advised that emotions interfere with the rational/logical parts of our brain. I was surprised to find, years later, that there is no evidence for this theory. In fact, research shows that outcomes for patients are better when doctors allow their feelings and emotions to be involved with their decision-making⁷. Doctors who are rated higher in compassion actually have better health outcomes in their patients⁸.

Compassion makes the system work better.

It's not just about individual practitioners, however. There are documented benefits of compassion at a system level – higher patient and employee satisfaction, lower staff turnover, shorter lengths of stay, fewer readmissions, and lower costs in procedures.⁹

The challenge of teaching compassion:

When we look at someone like "Dr House", we know that he is an extreme parody of "excellence". He is exceptionally competent and explicitly states that he won't let emotions cloud his reasoning. We can train up students to be "Dr Houses" by setting our competencies around diagnostic excellence (oh, and by teaching them how to be a pathologist, radiologist, cardiologist, surgeon and infectious disease specialist all at once...!).

But if we want to teach students compassion (and hopefully by now you are convinced that would be a good thing to do), we are faced with a difficulty. You see, the problem with medical and dental students is that they *don't learn what we expect, they learn what we inspect!* We know that



if we want them to learn something well we put it in an exam, and for the next few years all the subsequent students will know it very well. Yet human relationships are way more than competencies - they are more complicated than measurable outcomes or actions. So teaching students to be compassionate, and inspecting students' compassion, is not straightforward.

That said, compassion should drive us to competence. You can have competence without compassion, but I don't believe you can have compassion without striving for competence. So, I believe that focusing on improving compassion in our students will have the additional effect of increasing their competence as well.

The question that then needs to be answered is: how do we teach compassion? This is an area that is only just starting to be researched¹⁰, and there is great opportunity for Christians to input with the wisdom and example of Christ.

Some of my own thoughts on themes that Christians have to draw upon from our faith include:

- The importance of presence (Jesus 'did life' with humanity)
- The central role of mentoring / discipleship
- Understanding our identity as both servants and sons/daughters
- Recognising that we are wounded healers, and continually seeking the healing of Christ ourselves
- Meeting people where they are at, rather than pushing them to where we would like to be.

In summary, compassion is something we need to be teaching and nurturing in our students, ourselves and our systems. This means more than empathy. It means being competent to do something in response to illness, suffering and pain. Teaching compassion is something that Christians should be reflecting on and actively involved with where opportunity arises. ●

by Dr Natasha Yates (@DrTashY)

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teaches at Bond University as an academic GP. She is passionate about seeing health care professionals thrive, not just survive. Her belief that Jesus Christ is a person who can transform individuals and communities has helped her explore a range of non-technical skills within medical education and practice, including compassion, empathy, coping and resilience.

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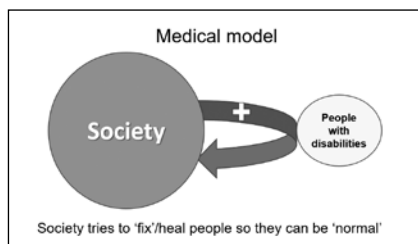
God Works through Disability, not Just Healing!

Disability prevalence is rising worldwide. The prevalence of chronic disease is increasing and now accounts for the majority of death and disability worldwide. And disability is, by definition, long-term or chronic. In Australia, 5.6 million people either have a disability, or care for a person with disability. On average, each of us in Australia will live for 20 years with a disability.

Disability and Doctors

As doctors, we interact with disability on a daily basis in our practice. But as Christian doctors, many of us do not have a clear theology of disability. When have we thought about how our Christian faith affects our approach to disability in our patients? How well are we equipped to deal with disability in our personal lives, community and church?

Our profession is more comfortable with approaching physical conditions and impairments with curative solutions. By contrast, with disability, healing patients is, almost by definition, not an option. Early on in medical school we are taught to see disability as linked to disease that needs to be treated. This is consistent with the approach that is known in the disability sector as the medical model. Whilst medical interventions can add much to the life of a person with disability, an exclusively curative approach risks devaluing people who cannot be healed. In many ways, people with disability can be considered a medical failure. Christians are called to go well beyond a medical model. Disability presents an opportunity for the Christian doctor to apply a Biblical response of love, affirming value and embracing those with disability.



In this article, I intend to outline not how we should treat people with disability, but how disability can treat us! We have much to learn from disability. After all, the Bible makes it clear that God uses the foolish things of this world to shame (or even treat) the powerful, wise and strong. The 'foolish', 'weak', 'lowly and despised' have an important role in breaking the strongholds of pride and conceit. I am sure we have witnessed some of these strongholds in our profession! And God loves to reveal His glory through those with disability, who in the world's eyes are foolish, weak and lowly (John 9).

Disability: A Paradox

As a preface to this article, we need to acknowledge that disability can be very painful. It likely is the experience of a good number reading this article. The disability rights movement might have us believe that disability is 'good' and that the problem lies with the environment – it doesn't cater for disability. This is known as the *social model* in the disability sector. Whilst I subscribe to and even teach on the social model, we can't paint over the very real element of pain and suffering associated with disability. We are created with DNA and genes coded for specific functions, but when they are disrupted or when we have an accident and break our back, we lose function. It is a real loss. I do not mean to belittle the pain and suffering that such disability can cause, and that many of

you might be experiencing. I know that pain personally through my beautiful daughter who has a profound disability.

A verse that has been special to me in the midst of pain is Isaiah 45:3: "I will give you treasures hidden in the darkness – secret riches. I will do this so you may know that I am the LORD, the God of Israel, the one who calls you by name."

I believe that God has purposes, or 'treasures', in disability and, as such, redeems it for His glory. A paradox exists whereby *at the same time* as experiencing pain, we can rejoice in this knowledge. Paul aptly describes this mindset in 2 Corinthians 6:10 in our being "sorrowful, yet always rejoicing". The Bible does not teach us to pretend there is no pain, and we are not called to rejoice because we have pain. But we can rejoice in God at the same time. Through my daughter's disability, I have been able to rejoice in understanding who He is and in seeing how He works in the midst of pain.

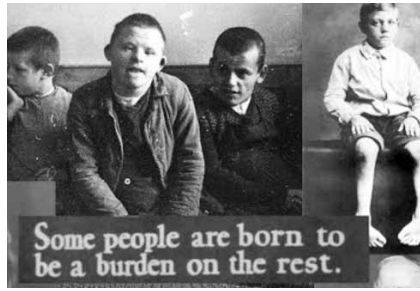
I believe that God works powerfully in spite of disability, and even through disability.

Disability: Non-Performing Assets?

Valuing disability in this faith-based way is counter-cultural to the dominant western worldview, and indeed runs counter to the medical model dominant in the healthcare settings where we work. Our society tends to value people according to what they can do and how substantively they contribute. Society might value a person with disability if they win gold at the Commonwealth Games. At a policy level a person is valued in

terms of economic value and output. Does this mean that people with disability are non-performing assets if they're not economically productive or showing their 'overcomer' prowess in some impressive way? Interestingly, or sadly, our government policy implies as much!

I love (and personally benefit from) the NDIS, but the only way this policy could come into being was through an economic rationale. The NDIS came into being largely through an argument outlined by the productivity commission. The logic goes like this: if unproductive units (people with disability and their carers) are supported to enter the workforce they can contribute to GDP, netting us an 18-22 billion-dollar return. Such economic arguments can potentially dehumanise those people with disability by valuing them according to their economic productivity.



Yesteryear attitude, T4 poster, 1939.

At its worst, does this assessment risk reinforcing the idea that if a person is not productive, or not valued, then why shouldn't they be euthanised? Just in case you think this is too far-fetched, this was the dominant thinking in the intelligentsia pre-World War II. It was an ideology that CS Lewis vigorously opposed. But why did these ideas not get much press after the 1940s? Well, when such a line of thought is taken to its rational endpoint then T4 becomes reasonable. T4 was a program in Nazi Germany whereby 200,000 individuals

who were mentally retarded, physically handicapped or mentally ill were eliminated over a five-year period. Very sadly, the medical profession contributed and aided this heinous program. And before you think this couldn't happen in our civilised society, tell me how many babies with Down syndrome does the medical profession contribute to eliminating for the sole reason that they have a disability? For Down's alone, 200,000 babies were aborted in the last five years because they were seen as having no value and were not consistent with our definition of success and happiness.

Disability in an upside-down Kingdom

Yet, I believe that society is a better place when we include people with disability. We are poorer without them. In order to value the contribution of

continued over page

The Upside-Down Kingdom

"The world says: Blessed are the strong and powerful, for they can get what they want.

Jesus says: Blessed are the weak, for my power is made perfect in weakness. (2 Corinthians 12: 9-10)

The world says: Blessed are you when people speak highly of you, for everyone will know of your good reputation.

Jesus says: Blessed are you when you are insulted, misunderstood and persecuted, for great will be your reward in heaven. (Matthew 5: 11-12)

The world says: Blessed are the knowledgeable and educated, for they will go far in this life.

Jesus says: Blessed are those who qualify in kingdom wisdom, for God has chosen the foolish things of the world to shame the wise. (1 Corinthians 1: 27-29, 1 Corinthians 2: 6-16)

The world says: Blessed are you when life is easy and you have everything you need, for that is

where happiness is to be found.

Jesus says: Blessed are you when you suffer, for suffering produces perseverance; perseverance, character; and character, hope. (Romans 5: 3-4, 2 Corinthians 4:16-18)

The world says: Blessed are those who live a good life, for God will use them.

Jesus says: Blessed are those who have messed up and know His grace, for he who has been forgiven much, loves much. (1 Timothy 1: 15-16, Luke 7: 44-48)

The world says: Blessed are the healthy and strong, for they can win races and achieve success.

Jesus says: Blessed are the feeble and weak-kneed, for God has chosen them to show His all-surpassing power and glory. (2 Corinthians 4: 1-12)

Lord, we live in a world that craves power and riches; forgive us when we conform more to the ways of

this world and help us to choose your path of humility and weakness. (Philippians 2: 1-11, Matthew 20: 28)

Lord, we live in a world that sees only the visible and judges on the outside; forgive us when we see only with our physical eyes and help us to see the invisible work of your kingdom around us. (2 Corinthians 4: 18)

Lord, we live in a world that is temporary and will wither and die; forgive us when we are so engrained in this world that we live as if this is all there is; help us to invest in your kingdom that will last forever. (Matt 6: 19-21, 1 Pet 1: 17-19)

Lord, you have made us to be in the world, but not of it. Thank you for sending Jesus to show us how to live here in this world. Give us eyes to see this world as you see it and to live here and now as citizens of your upside-down kingdom.

Amen

(Used with permission, Cheryl Stinchcomb)

GOD WORKS THROUGH DISABILITY, NOT JUST HEALING!

disability, an alternative framework for understanding 'success' is required. When we apply a different measure of success we can see value in people with disability. I believe we should view disability through the lens of an *Upside-Down Kingdom* worldview. As Christian health professionals, we should not judge success on criteria such as productivity, pleasure, power or prestige. No, as Christians, success relates to our faithfulness. Loving God. Growing in Him. Helping others to do likewise. Ultimately bringing glory to God is our measure of success!

Disability: A Severe Mercy for Successful Doctors

It was here that my own experience of disability challenged my unhealthy definition of success. Disability dragged me, kicking and screaming, into the *upside-down kingdom*. In 2011, I was successful in the eyes of the world. Recipient of a prestigious scholarship, undertaking a second PhD, working as a clinician and a director of various Christian development charities. Slowly and insidiously, my identity and meaning were becoming wrapped up in what I was doing and achieving. Success was becoming an idol and displacing God in my life. Disability was my severe mercy. When my daughter was born with a profound developmental disability it rocked my world and blew away my unhealthy ideas of success. When I applied to my daughter my definition of success, which had come to define me, then she was an ultimate failure and her life was meaningless. She would never achieve any of the things that had come to define me.

As I journeyed through the grief, I came to understand that my daughter has immense value and that I needed a new yardstick for success. Ultimately, that yardstick was the simple act of being faithful. This formed the title of a book I co-authored, entitled *Faithful Is Successful*. Disability made me live out what I once only professed: it's not 'doing' things that makes us successful in God eyes. It is 'being in Him' and being faithful. I believe my faith journey and spiritual growth have been tremendously shaped by my

experience of disability, just as, in some ways, Paul's journey was shaped by and dependent on his thorn:

"To keep me from becoming conceited because of these surpassingly great revelations, there was given me a thorn in my flesh, a messenger of Satan, to torment me. Three times I pleaded with the Lord to take it away from me. But he said to me, "My grace is sufficient for you, for my power is made perfect in weakness." 2 Corinthians 12:7-10

Disability has so much to teach us medical professionals who, almost by definition of the strict entry requirements, are 'successful' in the world's eyes. The real purpose of Paul's thorn was to keep Paul from becoming conceited. I believe that God gave me chronic disability in my daughter as a form of ongoing protection from becoming conceited!

"When my daughter was born with a profound developmental disability it rocked my world and blew away my unhealthy ideas of success."
.....

Disability: A Qualification for Ministry

Disability can also be a powerful tool in shaping those involved in formal ministry. In India, powerful preachers are held in reverence, and even labelled God-men. God-man is a term used to describe a type of charismatic guru who has a high-profile presence and is capable of attracting attention and support from large sections of society. We have recently been working with a group of pastors in India who have disabilities. Interestingly, these pastors are protected from being hailed as God-men because their disability identifies them as imperfect. People look at the pastor and see physical brokenness. But through this fragile clay jar the light shines and people see God at work in this person. The

disability points people to God, not the pastor. God is at work through the things that man considers foolish!

"But God chose the foolish things of the world to shame the wise; God chose the weak things of the world to shame the strong. He chose the lowly and despised things of the world, and the things that are not, to nullify the things that are, so that no one may boast in His presence."
1 Cor 1: 26-29

When one pastor had a daughter with profound disability, he thought he would no longer be able to be used by God. People would say, "Your God can't even heal your daughter!" But others saw how the church and pastor loved and cared for this girl, and as a result his church grew – not despite the disability, but through it. The pastor commented that his own experience of disability and brokenness allowed him to speak powerfully into the lives of people who are suffering and meet them where they are. As in Corinthians 1:4, he was able to pass the comfort he received from God on to the people he was pastoring.

Disability can be an upskilling in empathy. We know this as doctors. We are used to working in high-powered professions that are intolerant of people not keeping up. That is, until we have a crisis in our own lives. We make the best doctors when we have a personal experience of pain or illness. Perhaps we should see disability as a pastoral gifting or qualification.

Having heard many examples of how God works through those who have disabilities, I joined with several authors to write a book for the Lausanne Movement on People with Disability in Mission (not yet published). The Lausanne Movement has been progressive in recognising the role of people with disability in ministry.

"We encourage church and mission leaders to think not only of mission among those with a disability, but to recognise, affirm and facilitate the missional calling of believers with

disabilities themselves as part of the Body of Christ."

There are many examples of God at work in disability in the forthcoming book: a boy with autism ministering to the marginalised in South Africa; a man with cerebral palsy ministering in Africa; and, the mother of a child with Down's syndrome working in Indonesia. But you will have to wait until the book is released to read those stories!

Disability as a Blessing

So how do these seemingly weak parts, those with disability, contribute to the body of Christ? I share three last examples, though there are many others.

Biblical Interdependence – In Australia, the endpoint for most disability-oriented programs is largely to promote independence and autonomy. These are important aims for the NDIS. But for my friends in South Asia, this autonomy and independence looks very similar to loneliness! I feel that the perspective of Biblical interdependence is more consistent with how we were created. Disability and weakness should teach us interdependence in the body of Christ. That has been my experience as my wife and I have negotiated our ministry whilst living with disability.

1 Corinthians 12:12-26, with its concept of the interdependent Body of Christ, has become a defining Bible text for our journey. We are interdependent with friends, family and our church.

A Compassion Catalyst

In 1 Peter 4:10 we are told to use whatever gifts we have to serve others. "Each one should use whatever gift he has received to serve others, faithfully administering God's grace in its various forms." How often do we allow others to serve us? We are too proud! But disability allows a natural (or should I say, unavoidable) space for us to best act as we were created: to serve and be served in love. I have given up on being proud when someone offers help. I now willingly accept offers of help as I know I just can't do this life alone. What I have noticed is that not



Joel (permission given).

only is our daughter blessed but so is each of her care-givers. The Lord Jesus Himself said, 'It is more blessed to give than to receive.' My church has established a respite care program called *indispensability*, but I have decided to volunteer rather than take the respite. Why? Because I get blessed from serving these most beautiful kids and their grateful families.

"For doctors, the challenge is to move beyond understanding disability as a medical issue..."

Removing pretension – People with disability in our midst can free us to be ourselves, warts and all. Hauerwas and Vanier describe it like this:

"The mystery of people with disabilities is that they long for authentic and loving relationships more than for power. They are not obsessed with being well-situated in a group that offers acclaim and promotion. They are crying for what matters most: love. And God hears their cry because in some way they respond to the cry of God, which is to give love."

(Hauerwas & Vanier, 2008, p. 30)

I think of Joel, a friend with Down's. He is so genuine and not inhibited with worrying what others will think of him. He loves God and tells everyone

the same. He hugs people and longs for loving relationships. He is totally unconcerned with power, acclaim and promotion. This is such a breath of fresh air compared to the cannibalistic dog-eat-dog world of academia that I inhabit. We need more Joels, not more academics in our church! Yet there is a tendency for us professionals to surround ourselves with intelligent professionals, like ourselves. Our fellowship is much poorer when we do so. Worryingly, there is a tendency for successful professionals (read 'doctors') to be selected as deacons and elders in churches even though their status may have been a result of unhealthy ambition, unaware of who they are in God's image.

Conclusion

In this article I have been building a Christian worldview of disability that is perhaps radical to the medical profession. It challenges our idea of success. It convicts a world that assigns value by what we do, how intelligent we are, how much we earn and what power we wield. Disability enters this context and equips us to serve in ministry. For doctors, the challenge is to move beyond understanding disability as a medical issue, to experience the richness of engaging with disability as a Christian. Disability helps us embrace a revolutionary *upside-down* worldview whereby the seemingly weaker parts are indispensable.

Let me close with the story of Lawrence, a deacon of the early church in Rome, who clearly understood the value of people with disability. According to *Foxe's Book of Martyrs*, during the persecution of the early church Lawrence was ordered to bring the treasures of the church before the Emperor. He collected all the poor, sick, the lame, the elderly and disabled he could find from his church, and took them to the Emperor and said, "See, here are the treasures of the church!" It cost him his life, but he made his point. ●

by Dr Nathan

Dr Nathan is a Public Health physician in Melbourne. If you wish to be in touch, please email engagedisability@gmail.com

Rehabilitation, Disability, God and Us

A patient comes to you with an acute flare of chronic lower back pain, on a bucketload of opioids and demanding more. Does your heart sink a little? Or a gentleman with a history of brain injury who has failed to turn up (yet again!) to his renal appointment even if his kidney failure is deteriorating rapidly? Or a transtibial amputee with a diabetic ulcer on his contralateral foot who refuses to stop smoking? How do these patients make you feel?

By no means are the above examples typical of my patients. In fact, the exact opposite is usually what I experience – my patients are generally resilient, determined, innovative. I see them fighting harder for their wellbeing and health than most, often against systemic prejudice and discrimination. Rather, I use these examples to reflect on the emotions that it generates in us as healthcare practitioners: frustration, despair, hopelessness. While encounters with such ‘heartsink’ patients are not limited to rehabilitation, the nature of disability and the resulting physical, emotional, psychological and social changes often lead to more frequent and prolonged interactions with healthcare providers.

Although there’s a lot I could write about encountering disability from a rehabilitation perspective, I think the thing that has surprised and intrigued me the most working in the field has been reflecting on my own attitudes and how they have, or haven’t, aligned with the love, grace and truth of Jesus.

It starts early

From a young age, I think many of us are imbued with a sense of ‘us’, and the ‘other’. We are drawn to people like us, from picking kids we like on our soccer team at lunch, to the classroom cliques in high school and the clubs we join at university. We are shown, or taught

even, to ignore or reject or fear those who are different to us or those we don’t understand – different in sporting ability, in interests, in personality or social graces, in intelligence, in appearance. We value those who are like us, and are not usually taught to value those who are not.

We also strongly associate ability and performance with value. It’s something we talk about extensively with medical and dental students in CMDFA – how as a group of driven high achievers we have linked our self-worth with academic performance, rather than our true identity in Christ. This is the self-perspective angle of this attitude. The flip side of the same coin is the way we can link the worth of others to their achievements or performance. I think this is less strongly entrenched, but still can be very much a part of our makeup and societal culture.

“...often what patients value most is the person who is willing to sit and listen to them as they struggle with coming to terms with the huge life changes before them.”
.....


My earliest experiences with disability came at school – a boy who couldn’t participate in primary school athletics due to extensive burns and contractures; volunteering after school to help out with respite care for children with (what I now know was) cerebral palsy; the boy in the school band who was so very awkward and was relentlessly teased for not understanding social cues (probably with Asperger’s), but not at all understood by compassionless teenagers.

To be honest, as a child I feared the boy with burns with the balaclava covering much of his face, and his asymmetrical smile. He was somewhat of a school celebrity but I never talked to him. In sinfulness, I felt frustration for the ‘burden’ that the children with cerebral palsy placed on their parents. Even worse: surely, they could not make their parents as proud as I could by being chosen on a school community service team! I joined the teasing of the school band boy. I am deeply sorry for the grace and love I failed to show.

It persists

A lot has been written about a Christian perspective on otherness and inclusion, which I encourage readers to explore if they are interested. I think that whether disability is cognitive or physical, we often either fear or do not appreciate those who are different or cannot perform to achieve whatever it is we value. In sinfulness, we can look down on, or see those with disability as somehow ‘lesser’, defined by their inability to perform certain tasks rather than by the infinite worth God places on all of us. This is not necessarily obvious, and nearly never intentional, but I see people with disability treated as novelties, sources of frustration or even embarrassments by people they do not know, and sometimes by their own families and friends. Conversely, sometimes they are treated as objects of inspiration, a sort of perverse example to the able-bodied that if a person with disability can do something, surely anyone can?

Sometimes, we do or say things simply because we lack awareness. A colleague of mine described issues with attending many international conferences because of a lack of adequate wheelchair access. To my horror, I have had a patient with a dense hemiparesis in inpatient rehabilitation being told over the



“...to be treated as a valued, loved human being is something that all patients deserve and enjoy, even more when society fails to do so.”

.....

phone by government staff that their stroke impairments will improve – because their aunty had also had a stroke and she got better! I have heard well-meaning doctors nonchalantly list all the things the patients will never be able to do, berate people with chronic pain that their pain experience is their fault, and completely ignore people with disability in conversations that are about them, even when they are fully able to communicate!

Finding another way

For me personally, my patients teach me every day about striking the balance between medical expert, guide, and advocate. It sounds obvious, but to be treated as a valued, loved human being is something that all patients deserve and enjoy, even more when society fails to do so. I want to help explain knowledge of disease, medical interventions and prognosis... without downplaying the grief that can come with waking up without feeling or movement in your arms and legs. I fight to remind myself daily that the value of the aphasic, incontinent, hemiparetic, and likely confused patient before me lies not in their mobility, continence or ability to communicate, but in the way God sees them. I have learnt the joy of advocating strongly for my patients, without needing to feel sorry for them or praising myself for using my ability and position to help. I use my skills to remove obstacles to function, but know that often what patients value most is the person who is willing to sit and listen to them as they struggle

with coming to terms with the huge life changes before them. And yes, God loves the patient even if they will not listen to or do what we say!

In writing this, I'm conscious that there are doctors in rehabilitation medicine who have faithfully practiced for many years, and theologians who have written extensively and with great wisdom on disability. I'm so thankful to have had consultants who are devoted Christians who put their faith into practice, and have been role models for me. I am far from perfect, and I often fail to show the love to my patients as God does to us all – I have been guilty of similar attitudes to the examples I've used. My hope is that some of what I have shared can resonate with us as a community of Christian healthcare professionals, and we can continue to mould our attitudes and practices in response to the abundant grace that God has shown all of us – broken, sinful and imperfect though we are.

One of my most difficult cases in rehabilitation was very recent: a 30-something year old gentleman with a massive right hemisphere stroke, and every other complication of type 1 diabetes you could imagine. We journeyed with this fellow through months of rehabilitation, interspersed with bouts of ketoacidosis, sepsis, supraventricular tachycardia and kidney failure. He met the challenge with the brain of someone with a non-dominant hemisphere lesion: relative apathy about impairments and rehabilitation and the future, deferring

all decision-making to his parents. In turn, his parents refused to take him home until he could walk again – even though seven months after the stroke he had made nearly no functional progress, needing two people to help him with most tasks. I went through hours of meetings trying to do what we thought was best for him, fought every step of the way by his parents escalating their objections to every hospital manager they could contact.

The irony of two entirely contrasting views on advocacy in disability – our team with one perspective for the patient, opposed by his parents advocating from different beliefs and values – struck me, as I tried to manage the increasing frustrations and worsening attitudes of the team during the day, and pondered this article at night. Indeed, our reality is full of grey, full of challenges alongside opportunities. I pray that we can embrace the tension, embrace those who are different to us, embrace the 'other', embrace our failings with humility, and above all, be a conduit for God's love and good news to those around us – including those with disability. ●

by Dr Chris Chan

Chris is currently a pain fellow at St Vincent's Hospital in Melbourne, after having trained in rehabilitation medicine in Newcastle and Melbourne. Chris and his beautiful wife, Deb, both served in state student ministry in CMDFA during their undergraduate courses. Chris has also served as the national student staffworker for CMDFA.



Disabling Disability: We are in this Together

Disability is a major cost in terms of dollars and social cost in most countries. In resource-limited nations it is usually a greater issue – with higher incidence, fewer resources, a lack of training for professionals in the area of disability, and many social issues which contribute to making disabled children and disabled adults outcasts, or less able to be engaged in normal social life no matter what their intellectual abilities.¹ In addition, there is a lack of good local data to give accurate prevalence statistics and information on causative factors.^{2,3}

Over four years in Kyrgyzstan, with the assistance of UNICEF and other agencies, we have been able to see significant changes in the approach to disability, and also develop national guidelines to assist in the management of children with cerebral palsy (CP). This has been a multi-faceted approach based on the collection of local data, which has shed light on causation and given details of the overall picture of disability. Collaboration at all levels of health and government should assist in leading to a significant reduction in disability over time, and to a more evidenced-based and inclusive approach to children with disability.

Background:

About seven years ago, my wife and I were invited to work in the central Asian republic of Kyrgyzstan alongside other health workers. The initial invitation was to assist with neonatal work. However, things changed during the period between accepting the offer and arrival. The door to work in the area of neonatology closed and, due to work done previously by others, the door to work in the area of paediatric disability opened. This coincided with UNICEF commencing a project to fulfil



the UN goal of improving the health outcomes of disabled people. So began a working relationship with UNICEF which has proved to be very fruitful. In addition to UNICEF, work has been greatly assisted by JICA (Japanese International Cooperation Agency) and the Kyrgyzstani Health Ministry.

As a general paediatrician I had looked after many disabled children over my career, but had also been seconded to work in a tertiary paediatric rehabilitation centre in Brisbane over 2000 and 2001. Many of the skills gained there proved valuable in the work in Kyrgyzstan which has evolved and developed over time.

The medical system in most countries in Central Asia is very different from the west. There is a primarily didactic medical education system, with little or no clinical experience during training and very little problem-based learning. The system, inherited when Kyrgyzstan became independent in 1991, was very much based on doing what you had been taught, rather than on analysing data or looking at information gathered locally. Key to this way of thinking is establishing a diagnosis from which treatments or therapies follow.

Initially, the consultation work I was doing at a major hospital was in a

very different manner to what I was used to. Up to 130 disabled children underwent two week blocks of therapy every fortnight. Consultation was done in a large room with all the parents bringing their children in together. Each consultation was conducted with all the mothers and other children around, which led to group teaching for many of the parents about issues of disability. This has since changed due to the provision of a different room with better facilities, but this communal education was a useful part of the earlier consultation work. At the same time, data was collected in a basic format. This was later presented to UNICEF and the local Ministry of Health staff which then led to a whole process of training and interventions.

Pre-existing therapy implemented for children with a diagnosis of CP consisted of massage, hydrotherapy (when at the hospital) and some other therapies, including hot packs. There was little or no understanding of brain plasticity or expectation of improved function. Aspects of the massage therapy were quite vigorous, with little understanding about why such therapy was prescribed. In addition, many children received a multitude of medicines. It took time to learn what these medications were and, over time, it was realised that most were given routinely, with no evidence to support their use. The parents confirmed that they made little or no difference. It seemed that there was a belief that some medicines could actually repair the brain and that they should be used long term with the hope of eventual recovery. There appeared to be a lack of precision in giving advice to parents about individual cases, and a lack of understanding that good information

can be gained from a thorough assessment, which could guide both therapy and assist in predicting longer term outcomes.

The process of change:

The collection of data was useful in delineating the spectrum of disability present. This showed around 80% comprised CP, and about 20% other conditions – including genetic conditions (eg. Down syndrome), metabolic disorders (eg. Morquio syndrome), spina bifida, congenital rubella, spinal muscular atrophy, and others. Some conditions had not been diagnosed but were considered to be some sort of disorder without a name being given. The challenge was to find a diagnosis for these conditions in order to inform the parents about the implications for both them and their child (particularly if there was a risk of recurrence with future pregnancies).

Of the 80 % with some form of CP, around 30% had dyskinesia and 60% spasticity, with the remainder being either hypotonic or a mixture. On further history, we discovered that at least half of the children with dyskinetic CP had had severe neonatal jaundice and was due to kernicterus. A significant portion of these were mothers who were Rh negative with Rh positive husbands or partners. It was also apparent that only about half the women knew their blood group, and of those who were Rh negative, only a few knew what this might mean in terms of issues for the pregnancy. As one mother (who knew she was Rh negative with an Rh positive husband) said, “Why did someone not tell me about anti-D?” She had two normal boys and her third child was severely jaundiced and has severe dyskinetic CP.

Most of the severe spastic quadriplegic children had been ex-premature infants. Around 5% of children had been normal until they had some acute event – usually a febrile illness which required their admission to hospital. These then ended up with some sort of brain damage, either as a result of the illness (some had had meningitis) or maybe as a result of treatments given or not given (presumably resulting in hypoxic brain damage). Given that we only had access to parental or carer history it was not possible to clarify these issues further.



A grandmother and grandchild in Kyrgyzstan.

Photo: Dreamstime.

Data was presented to UNICEF staff and to Ministry of Health workers, which, because it was local and relevant, spurred them on to take appropriate action:

1. The data on the problem of Rh isoimmunisation has led to a new national policy advocating for all Rh negative women to receive two doses of anti-D, at 28 weeks and post delivery. They are also to receive it at other times of potential sensitisation, such as in the case of threatened or actual miscarriage, abdominal trauma, and so on. The issue of funding is still being worked out as mothers currently pay for this individually. There is also the bigger issue of ensuring that all women know their blood group before conception, or in early pregnancy. The estimated incidence of Rh negative in the southern population is 4%, and in the north probably around 5 or 6%. While this may sound low, this equates to around 6000 pregnancies annually being affected by this issue. Although this policy was updated in 2017, actual implementation will take time.^{4,5}
2. The need for advanced paediatric life support training was recognised. With the assistance of the Japanese Government and UNICEF, trainers from Lithuania came on two occasions during late 2015 to train groups from the north and south of the country. On the first occasion, a group was selected to become

trainers and then trained and mentored during their first training. This has now led to more than two hundred doctors and nurses being trained in acute paediatric life support. The course was held over two days, utilising mannikins and simulation in the training and testing of candidates. Evaluation of this training has shown that this trained group scored 30% higher than similar colleagues who had not been trained.

3. As it was evident that there was a dearth of skills in the allied health professions for assessing and managing children with disability, UNICEF funded training in this over one month in 2015. In 2017, the Japanese government (through their aid group JICA), funded two weeks of training to upskill local health professionals in current ways of assessing children with disability. They did this using the GMFCS (gross motor function classification scale⁶) and MACS (manual ability classification scale⁷). Healthcare professionals were taught how to plan and implement the basics of therapy with a view to seeing improved function. They did this using the ICF (international classification of function and disability) model, which is a holistic approach to therapy involving the family and child in decision-making. It incorporates diagnosis, how the disability manifests in this diagnosis,

continued over page >>>

how this affects activities and participation in day-to-day activities, what the child or family wish for in terms of improvements, and how the environment impacts all of this. As there is no real equivalent of physiotherapist or occupational therapist in Kyrgyzstan, doctors and the existing therapists have been upskilled in this ICF approach. Changes have been seen in the few years since this was implemented, which has encouraged local staff to learn and to think more about function rather than just diagnosis.

4. Along with this training, the Australian Cerebral Palsy database has been modified and is now established as a local database. (This database is also used in New Zealand, Sri Lanka, Bangladesh and other countries.) Over seven hundred children are now registered, though it will take more funding and expertise to collect data on children from other parts of the country. This data allows information from all maternity hospitals to be collated, and also for data on specific conditions to be examined.
5. Since it was seen that a proportion of children ended up with permanent brain damage following acute illnesses, the immunisation schedule was broadened to reduce this. Changes have been implemented in 2017 which should become widespread in 2018.
6. The training given in 2015 and 2017 noted big gaps in understanding many of the issues associated with children with disability. The idea persists that if we do the right things that brain damage can be cured. If only!! In 2016, a grant from the Australian embassy in Moscow established a telemedicine link with good internet access at the Ak Cyy hospital which is now becoming a tertiary training hospital. Education sessions now run weekly between this hospital and four other centres across the country. This is vital in continuing to improve the knowledge and clinical skills of the professional carers of disabled children. Most doctors do not have ready access to

the internet. Nor do they have access to up-to-date written reference materials. Therefore, this area of work in education, and in educating professionals as to how to look up information and analyse data, is an ongoing process. In addition to this teaching, a large number of up-to-date, evidence-based guidelines have been developed for national use throughout the government-health-based internet system.⁸

Other issues:

The incidence of CP in Kyrgyzstan has been estimated at around 20,000 of the 27,000 children who receive disability pensions. This translates to around 1% of the paediatric population under 14 years of age. It is likely that in reality this is higher, as there are children in remote villages who may not be registered. In Kyrgyzstan there is a shame associated with having a disabled child, and many mothers are divorced as a result. Perhaps a quarter of these children are left in the care of grandparents. This means that CP is around five times more common in Kyrgyzstan than in Australia (where incidence is around 2.5 – 3.6/1000 live births²). Although there is limited data, we are now collecting information on some of these social issues via the CP register. In time, this will give additional information which will help support children with disability.

Information on the data which has been collected and analysed so far has been presented at local medical forums, at health ministry meetings and at meetings organised by the World Bank and other key agencies in Kyrgyzstan. The change that is likely to make the most impact is the implementation of the Anti-D programme for mothers who are Rh negative. This, combined with effective management of neonatal jaundice using international guidelines, could potentially see the reduction in the numbers of children with CP by up to 30%. We have roughly calculated that only five months of disability pension is required to pay for two doses of Anti-D. (In reality it is likely to be more costly, but the costs are still very low compared to the costs of a disability pension for life, and very small in terms of the improved outcomes). However, it is not a simple

task. Education, awareness, enabling people access to the information they need for self-care, access for practitioners to good up-to-date guidelines for therapies – all are required to bring about change. One thing has been clear – the information has been difficult and shocking for some local professionals to take in. However, many are now able to see how they can effect change. By contrast, the existing system has been managed on people doing what they were told, not thinking about it nor analysing information. This mindset will take time to change.

Information was presented to the Departments of Education and Labour and Social Development, who are involved with education and special education, and the provision of disability pensions and aids, respectively. This has been of assistance in enabling them to see that many children with milder disabilities could attend normal schools (some children with disability have been excluded from normal schools). It has also revealed what number of aids, such as wheelchairs, are likely to be required for the population studied. These departments have become more active in seeking how best to utilise this information - specifically, to enable more children to be appropriately equipped so that they can function at the best level they can. This process, too, will take time.

Disabling disability and changing attitudes will take time, but things are changing. In the main city, a parent support group is established and part of their project is to increase the amount of accurate information available to parents and families. There are some rural villages where local people have established support and basic therapy centres for disabled children. These are seeing improved outcomes. In a shame-based society, there is often much shame placed on women with disabled children. This will be slow to change, but with supportive and informed parents and better access to good information, understanding of disability is improving. Key people have been supporting these changes at various levels in the community. Changes in management leading to improved outcomes have

encouraged many, and also changed the attitudes and expectations of many professionals involved in the disability area. The basic data that has been collected and presented clearly has been a catalyst for local people to bring about change within their country and to follow through on this at whatever level they can.

One of the key gifts we bring as a western-trained professionals is our education and training. It is hard for local people to understand the rigour of our training and the system in which we have trained. But it is this gift which gives us the ability to collect and analyse information and give a local perspective, so that the local professionals can understand and act on it. There has clearly been much good will from many people to see these changes begin to take place.

"You shall know the truth and the truth shall set you free." These

words from John 8:32 frequently come to mind. One of the key issues that has enabled success has been engagement with local professionals at all levels. This has been one of the most satisfying things for me as a professional. In a shame-based culture, it is important to understand that in order to gain trust and engage local professionals you work, not by looking at what is being done incorrectly, but by looking at how things can be done better. In particular, seeing how improved outcomes will be achieved by changes in therapies and improved use of medications. This enables them to see things differently and has facilitated the move to change. However, it has taken significant time and discussion. Evidence-based medicine (EBM) is a new concept for many and has not been part of basic training. However, this is changing and the improved outcomes they see using EBM is encouraging the change. But it will take time... ●

by Dr Nick Woolfield

Nick and his wife Fay have been living and working in the Central Asia country of Kyrgyzstan since 2013. Nick's main work as a paediatrician has evolved to be in the area of paediatric disability. They work with a local NGO, STLI (www.STLI.org) whose aims are to develop people to develop their country. They have four adult children living in Australia.



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People with Intellectual and Developmental Disability and Immunisations

Are they falling through the cracks?

Registered health practitioners play an important role in assisting people with intellectual and developmental disability (IDD) to access the national immunisation program (NIP²) through education and relevant referrals to GPs. These health practitioners include general practitioners (GPs), NSW nurse immunisers, primary health registered nurses (RNs), enrolled nurses (ENs) and pharmacists (who are accredited to provide annual influenza vaccines). However,

- little is known about people with IDD and their immunisation status,
- the literature lacks evidence (Lennox et al, 2007³, Goddard et al, 2008⁴; Momany, et al, 2011⁵; The Arc, 2017⁶), and
- reports of GPs and RNs advocating against vaccination have been made by AHPRA and NMBA, respectively (ACN, 2015⁷; NMBA, 2016⁸; ABC News Aug/Sept 2017⁹).

In recent months, we have also heard a lot of talk-back on radio and television concerning vaccination (or rather, non-vaccination) of children. The Australian Vaccination-Skeptics Network has been particularly active in Queensland where two young un-vaccinated adults have died of diphtheria. The most recent was reported by ABC News, 8 Feb 2018 (the previous death was in 2011; also see archived newspaper articles¹⁰). Queensland Health has reported more than 20 cases of diphtheria over the last 5 years. The AMA advocates for a 'herd-immunity' percentage of 95% vaccination rates across Australia to prevent outbreaks and safe-guard vulnerable populations that cannot be vaccinated.

The importance and administration of vaccines to protect vulnerable populations is well documented in the *Australian Immunisation Handbook* (AIH 2013¹¹, pp.13, Influenza, Down Syndrome -p252-immunocompromised people, and the homeless p.255), as well as in literature from the USA (Momany, et al, 2011⁵). Relevant updates include the National Centre for Immunisation Research and Surveillance (NCIRS) Fact Sheet¹² which provides information on the Australian Immunisation Register (AIR)¹³, and the Department of Human Services¹³ has many videos to inform people with disability how to access services.

“Many other vulnerable communities, e.g. the homeless, have in their midst people with IDD, who may also not access healthcare services.”

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The AIR has received government funding since 2015 and is linked to My Health Record which can be accessed by the public through the Australian Government's Digital Health Registry. These updates do, however, depend on an individual's health provider updating those records.

Due to the nature of people with IDD being increasingly supported and cared for in a non-nursing model, people with IDD may not be routinely referred to GPs and Primary Health RNs for immunisation – thus falling through the cracks despite the good intentions of person-centred care (Goddard

et al, 2008⁴; Webber et al, 2016¹⁴, ACN, 2015¹⁵). Many other vulnerable communities, e.g. the homeless, have in their midst people with IDD, who may also not access healthcare services.

All of these people are worthy of our attention, support and care. “We are so conditioned by our society that it is difficult to truly believe disability is meant to be part of this world”. (Best, 2012¹⁶)

Case Scenario:

Initials: ANON

Age: 30

Case notes: IDD and complex health needs: epilepsy, chronic neurological conditions and prescribed corticosteroids (AIH 2013¹¹, p.478; p.253, congenital limb malformation; and difficult access for injection sites p.74). This person is also immunocompromised.

Immunisation status: childhood vaccines up-to-date; annual influenza vaccine; adult vaccines – pneumococcal (AIH 2013¹¹, p.327)

Action required: Review records; document serology and gain consent for adults lacking capacity (AIH 2013¹¹, p.27) from a substitute decision-maker. Refer to the enduring guardian legislation in NSW.

What safeguards are in place for this person?

- Disability Inclusion Act 2014¹⁷
- Health Care Plans (accessed only after valid written request)
- *Australian Immunisation Handbook* 2013: Defines the importance and administration of vaccines to protect vulnerable populations (AIH 2013¹¹, pp.9-11, 36, 104-175, 104-175, 204, 223, etc)
- with relevant digital updates

Disability Inclusion and the World's Poorest People

When Cate and I, and our three small children packed up to head to West Africa at the end of 1989, we had Matthew 9:36 on our CBM prayer card: 'When Jesus saw the crowds, he was gripped with compassion for them, because they were harassed and helpless, like sheep without a shepherd'. At that time, we had no idea how much more meaning that verse would gain. This would be through meeting generous and resilient people in some of the world's poorest communities in their struggle for survival, but also as we faced our own struggles.

The Cycle of Poverty and Disability

We worked firstly in Sierra Leone, seconded to the Baptist Church, and then in Niger. Our programmes sought to bring improved quality of life to people with disability. At that time, Sierra Leone and Niger were ranked at the bottom of the UN Human Development Index. People with disability make up 20% of the world's poorest people. The people we had the privilege to work with were (and remain), among the world's poorest people.

Together with activities in farming, gardening, animal husbandry, small business and general community development, our programs strived to build access to health, rehabilitation and education. This work was extremely encouraging as we saw people's lives changed, and as we learnt so much from our local teams and people living in these poorest of communities. Our work could also be very discouraging. On a daily basis, we witnessed the grinding cycle of poverty and disability, with each leading to the other. We



Cate and David Lewis.

encountered enormous need, which we could not possibly meet.

Learning from our experiences

In 1992, I had a profound experience. In a remote Sierra Leonean village, I met a young mother named Mariama, who had bilateral cataracts. We discovered that not only had Mariama developed cataracts in her mid thirties and been totally blind for three years, she had also been profoundly deaf since she was a small child, (quite possibly due to her mother having had rubella during

"Mariama received cataract surgery through our program. It was wonderful to see her return to her community, able to fully care for her children again."

.....

pregnancy). Mariama had remained an active member of a very caring family and community, but I still struggle to think of the isolation she must have experienced over those years of being both deaf and blind.

Mariama received cataract surgery through our program. It was wonderful to see her return to her community, able to fully care for her children

again, go to the farm with her husband, and to the market where she communicated with her friends, using her own sign language.

I reflected on the importance of our program. It had enabled Mariama to receive medical care, and even if surgery had not been an option, we would have ensured she was part of rehabilitation activities. What worried me was all the other Mariamas across West Africa. What was their situation, what was happening to them?

Sierra Leone's Diamond War and People with Disability

Sadly, at this time, Sierra Leone's brutal rebel war, fuelled by greed for diamonds, was gaining momentum and destroying innocent communities. Our working area became flooded with desperate, displaced people seeking safety, shelter, food and medical care. CBM generously provided resources for us to establish a humanitarian program focused especially on people with disability, their families, and

other marginalised people. While this program achieved a lot, that period remains one of the most difficult that Cate and I have lived through. Personally, I found it gut-wrenching, and also a test of my faith, to see the horrors endured by innocent village people who wanted nothing more from life than to bring up their children in peace and security. I especially thought about the people with disability, who

failed to access any sort of humanitarian programme. We know many of them died trying to reach safety.

Leaving Sierra Leone and Reflecting

In mid-1993, we moved with the family to the beautiful country of Niger. Over the following years, I found myself reflecting on many things. How do we understand God in those times when his love is seemingly totally absent, only to feel his love totally overwhelm us at other times, in situations of absolute tragedy?

One of my key reflections was on the situation for people with disability. How can all the Mariamas in need of health and other services gain access? And moreover, what about the countless numbers in need of assistance in desperate humanitarian situations?

I came to realise that while specialist programs for people with disability are essential to meet their specific needs, it is via their access to 'mainstream' programs that their overall needs and also rights, will be much more fully met in all situations.

Disability Inclusion in Australia's Aid and Development Program

These realisations triggered CBM Australia in the late 1990s to start an advocacy program on 'disability and development' to the Australian non-government organisation (NGO) community, as well as to the government. Thanks to the dedication of many committed people, including people with disability, we saw this cause adopted strongly by the sector. In 2002, the Australian Council for International Development unanimously passed a policy encouraging all its member agencies to build disability inclusion into their programs. In 2008, the Australian Government put in place their *Development for All*¹ strategy aimed at seeing Disability Inclusive Development integrated into the whole aid and development programme.

It has been wonderful to feel God's enabling in these outcomes and in the ongoing journey to see people with disability fully participate in and contribute to development programs, be they in health, water, sanitation



Patients after cataract surgery at Caritas Takeo Eye Hospital, Cambodia.

Photos: CBM.

and hygiene promotion, access to clean energy or in any other sector. We also now have the Convention on the Rights of Persons with Disabilities,² Sustainable Development Goals ('Leaving No-one Behind')³, Universal Health Coverage⁴ and other instruments to assist in driving the inclusion agenda forward.

Reflecting on Faith

I opened this article quoting Matthew 9:36: "When Jesus saw the crowds, he was gripped with compassion for them, because they were harassed and helpless, like sheep without a shepherd."

When we moved to West Africa, we arrogantly saw ourselves as bringing hope to people in poverty, and I guess in some small sense and with God's enabling, we did see hope come into the lives of many families. However the reality is that some of the poorest, most desperate people gave us much more hope and encouragement than we ever gave to them. Once close to the war front in Sierra Leone, we found a young woman named Jeneba who we carried to the safety of our project. She had witnessed her whole family being killed by the rebels, and had then over a period of months become totally blind, due to River Blindness/ Onchocerciasis while hiding with friends in the bush. On an occasion when I was very distraught by the advance of the war, it was Jeneba who encouraged my faith and hope with her gentle words, 'Don't worry, Mr David, everything will be alright, everything is in God's hands'.

As I have become older, I am aware that my faith has become more holistic and even more realistic in a broken world. Perhaps the biggest lesson I have learnt is that if we can put our pride aside and seek to practise humility in some measure as Jesus did, we can learn something from every encounter, which will strengthen our personal and professional lives. ●

by David Lewis OAM

David is CBM International's Focal Point for 'Inclusion in Eye Health' and 'Environmental Sustainability'. With training in agricultural science, community development and Christian missions, David has worked with CBM since the end of 1989. In 2014, David received a Medal in the Order of Australia for the role he played with others in bringing disability inclusion to the Australian aid and development sector, together with his contribution to Disability Inclusive Development programs around the world.

Some useful resources

- Strengthening Environmental Sustainability and Inclusion in Health and other Development Programs: http://www.cbm.org/article/downloads/54741/Improving_Environmental_Sustainability_and_Accessibility_in_Eye_Health.pdf
- *Inclusion Made Easy* (in Health, Eye Health and other development activities): <https://www.cbm.org/Inclusive-Development-246768.php>
- Luke14: a CBM initiative, which helps churches become a place of welcome and belonging for people and families living with disability: <https://www.cbm.org.au/get-involved/church/>
- Include Us: 'Women and girls with disabilities often experience multiple layers of discrimination. This short film *Include Us* highlights their unique experience, the contributions they have to make to their communities and the importance of their inclusion in all development efforts. Include us!': <http://www.cbm.org/International-Day-of-Persons-with-Disabilities-2017-533868.php>
- Australian Council for International Development, Practice Note https://acfid.asn.au/sites/site.acfid/files/resource_document/Disability-Inclusive-Development-Practice-Note.pdf

Footnotes

1. <http://dfat.gov.au/about-us/publications/Pages/development-for-all-2015-2020.aspx>
2. <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>
3. <https://www.un.org/sustainabledevelopment/sustainable-development-goals/>
4. http://www.who.int/universal_health_coverage/en/

From Exclusive Banquet to Inclusive Party

Why is it that people with disability find Christian churches more exclusionary than other places in society?

There has been a long history of segregation and isolation that seems to be changing in society, but perhaps the church is lagging behind. While church leaders and theologians are giving thought to inclusion, CBM Australia¹ is keen to resource churches and their leadership with tools to aid their thinking and practice. This work with churches builds on CBM Australia's desire to build inclusion into society, and to ensure that the participation of people living with disability is a high priority. We are committed to Australian churches who support our work internationally. This article will discuss the theology behind CBM Australia's church engagement program, the significance of Jesus' interaction with disability and how

this provides a model for churches to follow.

The significance of a meal

CBM Australia's work in empowering churches to be more welcoming of people with disability and their families is called Luke14.² The name is derived from a particularly important occasion when Jesus was invited to a meal with some high-level synagogue leaders. We read "the people were watching him

"The exclusion and loneliness experienced by people with disability, and also their families, is a poor reflection on our society and our church communities."

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closely" (Luke14:1 NLT) as he sat down with this important group in the home of the leader of the Pharisees. Perhaps they were expecting some fireworks? If so, they were not disappointed! The significant words spoken by Jesus to his host sets the tone for us:

When you put on a luncheon or a banquet, don't invite your friends, brothers, relatives and rich neighbours. For they will invite you back, and that will be your only reward. Instead, invite the poor, the crippled, the lame and the blind. Then at the resurrection of the righteous, God will reward you for inviting those who could not repay you." (Luke 14: 12-14 NLT).

Jesus goes on to tell the parable of the great feast and we find radical confrontation for those at the feast and for us today. Joel Green writes in his book, *The Gospel of Luke*,



Invitation to the Feast, Eugene Burnand, 1899.

that “orthodox conventions have as their consequence exclusion of the poor” and “Jesus’ counterproposal, if conventionalised, would negate tendencies toward exclusionary social boundaries and the value of reciprocity.”

Amongst other things, this is a story of restored community. Significantly, the story is told not just at a meal, but about sharing a meal. Historically, but also today, many people living with disability are not invited to such a meal or to a ‘table of communion’. The exclusion and loneliness experienced by people with disability, and also their families, is a poor reflection on our society and our church communities. Jesus’ description of those who are the second and third tier of invited ‘guests’ could easily describe those who are excluded today as well. As many churches know, when a free meal is offered, whether it is breakfast, lunch or dinner, the majority of people who come along are people who live with disability. Is it because they have no food or because they would prefer to eat their meal with company rather than alone? It is good to offer such a meal, but imagine going further – envisioning those people as part of our church community and being invited to eat meals in our homes.

Redefining disability

Another distinctive feature of this story about Jesus and his parable is the absence of healing. We typically associate the combination of Jesus and people with disability with a story of healing. However, it is most definitely ‘come as you are’ – you are welcome as a guest at the banquet with your disability. This is wonderful news for people who live with disability! As with the banquet, so in our churches we need to welcome people as they are and not see people as incomplete or imperfect because of their disability. Many Christians living with disability or parents of a child with a disability find this an important factor in whether they feel welcome or not in a church community. There is an uneasiness, and maybe even embarrassment, present if healing (or if not, why not) is a constant question. People value prayers, including people with disability, but prayer should be a consultative process not assumed.

In the second ‘sending out’ of the servants, the rich man tells them to “urge anyone you find to come” (Luke 14: 23 NLT) and this conveys a sense of reluctance by those being invited when we might expect them to be eager to enjoy the banquet. This is also true of people with disability and families who may be reluctant, even though eager to be part of the community. Their reluctance often stems from previous experience of rejection, confusion about what they have been told about their faith and their disability and,

“The unwelcome are now welcomed and become the centre of the feast!”

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generally, the challenges of being able to get to a Sunday morning meeting or other gatherings. The use of the words “sending out” and “urge” indicates a lot more than simply putting out a welcome sign, letterbox drop or radio advertisement. It does mean go out and meet people, get to know them and then make a meaningful invitation to be part of a loving and accepting community that will celebrate who they are.

As we contemplate this story, we finish with a picture of a very different kind of banquet. The unwelcome are now welcomed and become the centre of the feast! What would have they brought if they couldn’t repay the host? Jean Vanier, the founder of L’Arche⁴, writes that “people with intellectual disabilities led me from a serious world into a world of celebration, presence and laughter: the world of the heart”. He writes that those who are open about their vulnerability and weakness enable us to “discover the deepest part of our being: the need to be loved and to have someone who trusts and appreciates us and who cares least of all about our capacity to work or to be clever or interesting.” This sounds very enticing and we can only wonder if the host of the meal that Jesus was attending was forced to compare that with the competitive and stressful meal he was hosting!

CBM Australia’s Luke14 work is not just about enabling churches to be welcoming. We believe that the people who make up a church community are missing out on what people like Jean Vanier have experienced and celebrate. Our experience is that people who have found themselves unwelcome and excluded have a significant contribution to make. The apostle Paul writes, “In fact, some parts of the body that seem weakest and least important are actually the most necessary” (1 Corinthians 12:22 NLT). Perhaps we need to pause and consider our motives for putting up or removing barriers to the participation of people with disabilities in our Christian communities. Whose needs are being met and is this an act of benevolence or a confession of need? Many churches around Australia can testify to the benefits they have received because of the presence of their friends who have experienced exclusion elsewhere and are now an important and necessary part of their part of the body of Christ. ●

by Robert Nicholls

Rob is the Church Relationship Manager at CBM Australia where he works on partnerships with churches



on behalf of CBM and Luke14. Rob worked in leadership roles in community services for 30 years, including Wesley Mission Melbourne, before moving to a combination of working in the church as a pastor and training and coaching consultancy. He took up the role at CBM in 2010 to follow his two passions of the church and people and people who live with disabilities.



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1. CBM Australia is an international Christian development organisation devoted to improving the lives of people with disabilities in the poorest places on earth. Poverty and disability go hand in hand, creating a cycle of inequality, isolation and exclusion that leads to the most extreme forms of poverty. (www.cbm.org.au)
2. Luke14 is a CBM initiative that helps churches become a place of welcome and belonging for people and families living with disability.
3. Joel B. Green, *The Gospel of Luke*. (Grand Rapids, MI: William B Eerdmans Publishing Company, 1997) p552-553
4. L’Arche is an international federation of communities with the aim is to create communities where people with and without an intellectual disability live relationships of mutuality and trust.
5. Jean Vanier. *Becoming Human*. (New York: Paulist Press, 1998) 89

Gaining Sight

Sight is one of the things that I, even (embarrassingly) as an optometrist, take for granted. Patients tell me every day about their 'disability' – what they can or can't do because of their eyes (i.e. why they have come to see me). Yet I quickly forget the things of life I am helping them with and get bogged down in the parts that are mind-numbingly repetitive – "Which is better 1 or 2?". My mind then wanders to other jobs that I am convinced I would find far more interesting. However, despite my myopic self, thankfully I have not yet moved on from eyes.

It was as a teenager that God impressed upon me his care for parts of the world that had far less than most of us in Australia. I chose my vocation with the intention of putting my skills to use in places where they were otherwise lacking. I was sheltered and idealistic, wanting to 'help the poor' but also keen for an adventure. Even from a tentative start, God has worked patiently with me and I have been gifted a myriad of life-enriching experiences and people who I never would have met otherwise. In wanting to help others, I have received far, far more back.

Meeting and hearing the stories of those who have lived their whole lives without access to eyecare because of poverty but then had their lives literally transformed, has opened my eyes to a world that I don't always want to see. Disabilities caused by often-treatable poor vision are in some ways familiar. However, the impacts are potentially devastating for families who already have nothing to spare. I have met:

- children deemed blind who have been hidden at home all their life rather than sent to school;
- other kids who may have had better vision, but were still unable to study properly to get through school;
- people who have lost social abilities and connections because they were unable to see other people's faces and expressions;



- people losing their livelihood when they reached their mid-40s since they could no longer see to sew garments as a tailor, or who could no longer tutor or teach at a school because they could not read the writing in the books;
- older, previously productive, women who have become severely depressed as they are blinded by dense cataracts and become housebound, unable to cook or eat without help and a burden on family.

Out of sight, out of mind is a trap I easily fall into, but seek very much not to be by the choices I make. My current professional life consists primarily of visiting remote Aboriginal communities in the Northern Territory. This is combined with a mix of traditional optometric practice at home and interstate, mobile clinics to detention centres and schools with high migrant and refugee populations, and overseas work. Amongst them are profit and non-profit, Christian and secular, paid and unpaid work. The balance of the different types of work has evolved over time as I have sought experience

in different areas, and I'm sure it will continue to change. One important and deliberate decision I have made in recent years has been to be a locum. Despite bringing a degree of income uncertainty (which thankfully has never been a problem), I relish the freedom and flexibility it gives me to be available to take up opportunities that arise overseas and in Australia among groups that are disadvantaged, without the restrictions that come with a permanent job.

The main peoples with whom I have been involved in an ongoing way the past fifteen years have been in Bangladesh and Mongolia. Over the past nine years or so, also Indigenous Australians, as well as several short one-off stints in other countries in Asia. Whilst my 'ideal' has always been to move to a country for several years and learn the language and culture in order to be the most effective in my work and relationships, this does not seem to have been the plan for me.

My initial experiences in countries have all begun with 'service delivery' – performing clinical services for the local population. However it didn't take long to realise that to provide the ongoing eyecare that the people really need – that isn't reliant on my (or others') intermittent trips – requires training of locals. It is in this direction I have sought to be more involved over time and as opportunities have surfaced.

Bangladesh was my first developing country trip clinic. It was in 2003, when I had gathered just two years of Sydney experience. I put my hand up to do follow-up eye tests for those who had recently had cataract surgery. However, these people had not received the lens replacement implants that I was used to back home. They needed me to prescribe them those super-thick coke-bottle glasses, without which they were still almost blind. It was one of those intense learning and humbling experiences, totally out of my comfort zone. Whilst having to cross language and cultural barriers and very much



learning on the job, I would find myself each day with vast queues of older people waiting to see me. They would arrive from early morning, sometimes having walked a number of hours to get there, only to then sit (or crouch) outside and wait more hours until it was their turn. It is among these people that I have admired some of the most innovatively repaired glasses I have ever seen!

Five years later, eyecare training had developed in Bangladesh and there was opportunity to mentor some new locally trained clinic staff. I stayed for an exhausting ten weeks where I felt I made little progress but did at least gain their respect. I returned in subsequent years for shorter program evaluation and training visits and am keeping abreast of planned vision centre developments.

The year I spent in Mongolia I worked with local staff and a British optometrist doing clinics in both the city and in remote locations all over the country. There were similar crowds lining up for eye tests at times, but the patients might have come in from their gers on horseback, or even camel across the vast steppe. Salty tea, chunks of pure fat and various dried milk products that, to this day, still taste like chalk to me, were offered to us regularly as part of our sustenance.

Over that year and in subsequent years,

“Meeting... those who have lived their whole lives without access to eyecare because of poverty but then had their lives literally transformed...”

.....

as I have returned to Mongolia to do more remote clinics in partnership with various local colleagues, it has been apparent how unusually common complex refractive errors are among Mongolian people and even more so in particular regions. There has long been a need for local personnel in remote locations to be trained well in refraction in addition to general ophthalmology but for years there has been resistance from key figures. One of the most exciting things I've seen evolve over the past few years has been this movement, initiated by a new generation of local eye doctors,

to provide refraction training to the many doctors who are keen to learn to prescribe glasses, and to formally incorporate it into ophthalmological training programs. My role in this has been focused more directly on mentoring the newly-trained doctors from an initial pilot refraction course. I have also been closely involved with the inaugural course run by the Mongolians last year. A second course is being planned for this year. As a result of this training, many of the outlying provinces in Mongolia now have a permanent local eye doctor trained to prescribe glasses.

It feels like only a start, but there is a certain satisfaction in seeing, after so many years, all these places in which I have done one-off clinics now having trained doctors they can go to anytime. I used to want to return to live for several years in Mongolia, but it seems that not doing that has enabled me to stay involved there (and elsewhere) much longer and perhaps more helpfully. ●

by Stephanie Chen

Steph has a home base in Sydney where she grew up and is part of a local Baptist church. With all her travel to different places it is important to her to still keep up with her friends and family. When on her own she enjoys birdwatching and has developed an appreciation of Australian native plants, many of which are easily able to survive her frequent absences!



Editorial – from page 3

the Christian Church, to enter into hopeful solidarity with our disabled brothers and sisters. May we do so until that day when “there will be no more death or mourning or crying or pain.” (Revelations 21v4). ●

Paul Mercer
Editor



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Reflections on Learning from People Living with Disability – from page 21

my relationships with all people and, especially, with Jesus. I am a better person for having stumbled into this calling and I have no doubt God called me to what at first was simply a job. Now, it is far more and I cannot imagine a life without the beautiful contribution of people who are described by their disability and their families. I need that continuing contribution because I continue to need maturity and growth through rejecting the competitive and high-

speed world in which I live, instead moving at God's pace. ●

by Rob Nicholls

Rob has forty years experience in human services with Koomarri ACT, Wesley Mission Melbourne and UnitingCare Community Options. He is also an ordained pastor. He now works at CBM Australia where he works with churches to tell of CBM's work of ending the cycle of disability and poverty and assisting churches to include people with disabilities through an initiative called Luke14.



Wholistic Care through Charity & Development



Indra has been wheelchair bound for 20 years. DHERSEC is supporting his son Bhim's study towards a BEd. This would secure the family's future.

social capital and adequate resources may result in little disability, if the affected person has the spirit and resilience to overcome it.

Some people get upset about the word disability and question whether it is about inability, different ability, abnormal ability? 'Abnormal' – what is normal, anyway? Disability and handicap are concepts that depend on worldview. A way to rejig our thinking (worldview) is a typology framed by Stephanie Hubach, that I found

"But when you give a banquet, invite the poor, the crippled, the lame and the blind." Luke 14:13

As a GP for forty years I have a proclivity for running late. This is due to giving more time to those who need it, especially people with disability and those who are vulnerable in other ways.

I may lose the busy person needing timely service, so my practice shapes itself towards those who can put up with me. No doubt I am categorised by patients, but I won't bother to put myself in a box. Jesus categorised people (as poor, crippled and lame) to get across his meaning, but not as criteria for who would or would not be invited. He could have said, "the vulnerable, the disadvantaged and the powerless," as he seems to be most concerned for those who are socially excluded or disadvantaged. His example for the disciples is to invite all the people you would not normally think of inviting. I like the descriptor "lowly" (low in status and importance, humble, meek) found in Mary's Song of Praise (Lk 1:52). "God my Saviour" has "lifted up the lowly".

My point is that disability is a loose concept and is not for exclusion purposes, nor for defining criteria for some benefit. It is not for separating out the imperfect as unworthy, nor for deciding who does not get a disability support pension (DSP). Have you met any new recipients of a DSP lately? In this town of Port Pirie, there is a total moratorium and disregard of medical recommendations for DSP. It is an analogue term rather than a digital one, hence the huge problem of those who fall between the cracks of

categorisation in accessing specialised benefits, especially children with special needs.

Impairment is a measurable medical concept that has less to do with social constructs. Would a system of impairment support benefit be fairer than the DSP? Or would that level playing field be like giving the aged pension to all over the arbitrary limit? Physical and mental impairment may result in disability (a performance issue) and handicaps (social barriers). Disability may spiral a family into poverty. The poor are more prone to preventable disability. If we use the word poor broadly we are also talking about those with low social capital, dysfunctional relationships and limited parenting skills. A combination of these factors is not infrequently found clustered in less desirable suburbs and towns. On the other hand, impairment experienced in the context of strong

The boxed stories illustrate the wholistic integration of approaches taken by DHERSEC – assisting fulfilled and independent futures.

Home visit to an abdominal pain case found her "not at home". She was evidently better, but some serious pathology was found on CT abdomen that needs further investigation. She lives in a squatter settlement next to the dry river bed on the outskirts of Dharan. She is mother of 2 daughters, one of whom is now a widow after suicide of poverty struck, depressed husband. Her other daughter 18 has dropped out of school and got married. This family was found by DHERSEC worker Asha following the illness and death of the mother's sister to thyroid cancer. The family



survives by collecting and smashing stones from the river for building material. It is possible to earn Rs5000 (\$62) per week, but some is taken by the contractor. The stone breaking industry is well known for exploitation.

quoted when searching for Christian approaches to disability:

1. Disability is an abnormal part of a normal world.
2. Disability is a normal part of a normal world.
3. Disability is a normal part of an abnormal world.

While the first view is the one commonly held, the second may be a rights-oriented reaction. The third derives from biblical reflection on the way God sees it. Creation was wholly good until marred by sin and its consequences of suffering, death and imperfection. Disability is a normal part of this broken abnormal world, and we see injustice, discrimination and prejudice compounding the difficulty. We see lack of access to health, education and opportunity for those least able to compete. These are the handicaps we place in front of people with disabilities, as we are competitors ourselves. Semantic ruminations reflect the struggle in which we are conflicted.

Recently the NDIS (National Disability Insurance Scheme) has come to town and there seems to be a flurry of people coming in with forms to complete. There is an air of optimism among my patients with disability who are still on NewStart payments. A day will come when they no longer have to make endless and meaningless job applications. My view of the situation in Australia is sometimes jaundiced; but it is counterbalanced by my ongoing experience in Nepal.

I have been privileged to be associated with the "Disable and Helpless Rehabilitation and Service Centre" (sic) from before its foundation in 2005. Mary and I were medical missionaries with CMS setting up a department of family medicine in a teaching hospital in Dharan in eastern Nepal. In a search for community services for a brother and sister with Friedreich's ataxia (well, that was my diagnosis), I got to know a community group representing people with disabilities, their families and supporters. Medical Mission Aid (MMA) in Victoria responded to a request for funds, DHERSEC was formally established and has since grown as a disabled people's organisation (DPO) that impacts thousands of lives in a very poor country. The budget

Vocational training – Motorcycle maintenance

Om Bdr was attacked by thugs 10 years ago. His right hand was amputated and left forearm fractures internally fixed. DHERSEC helped for medical expenses and more recently sent him for a six-month motorcycle mechanic course. He established his business two years ago with the help of a DHERSEC loan and did teacher training part time. Now he has been appointed to teach mechanic trainees in his business. Currently the third group of five are with him for two months. For this he receives Rs6000 (\$75) per month. The trainees receive Rs1500 per month. Om gives the trainees a share of the profits from the business. The traineeship is a 60:40 partnership between DHERSEC and the Municipality. Although agreement



A motorcycle maintenance trainee.

was reached about this and other training partnerships it is not certain the Municipality will pay its portion.

Om Bdr's daughter recently had pneumonia complicating known VSD – hole in the heart. Surgery is planned when she has gained sufficient weight, meanwhile taking heart medicine and being reviewed.

"As a GP with a whole person approach, my aim is to help people towards reaching their full potential."

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of around AUD\$50,000 still comes from MMA. Most of the money helps individuals and their families directly. Long term relationships with families have seen life transformation that is best illustrated through stories.

Some aspects of its work set DHERSEC apart. For those seeking help, there is no age restriction and no restriction by type of disability, health problem or social problem. Some disability organisations are specifically for children, or visually impaired etc. Some are for physical disabilities but not for mental ones. The word "helpless" in the name has unfortunate connotations in English but does describe the lack of help available to poor and outcast people in the local context. Helpless is akin to lowly. It includes single mothers, the deserted aged, internal landless migrants, alcoholics and other misfits. Just as my running late behaviour sifts my patients, there are

aspects of DHERSEC that make it less attractive to those with the means and education. Thus, the allocation of resources has been enough and a bit like the loaves and fishes. DHERSEC has been very resourceful in networking and partnering. Its work has had a multiplying effect through shifting of attitudes and empowering approaches.

We began with medical help, aids and appliances. Later we added support for education, then vocational training and finally small business loans. Throughout there has been investigation of family circumstances, advocacy for individuals and highly personalised service provided by the staff who have no qualifications in the sector. They have been active in the public domain through outreach activities, public meetings and publicity.

A reality check about remaining stigma and social expectations of people with disability in Nepal came when talking to a 30 year old woman in a wheelchair who I have known for over 10 years. She is now almost independent as a seamstress, but living in a room of her brother's house. Would she marry? It was unthinkable.

Practice and ministry are the same thing. What a delight to read something

continued over page >>>

my wife Mary, wrote after our trip to visit DHERSEC in January.

We visited with Sita, a woman who has supported unwed mothers and their children, 26 of whom still live with her and go to school regularly. Sita and her husband Lalit volunteer for DHERSEC. "You don't know what God has done through Dr Owen", she said. "Did you know that there are six house churches out in the forest community – all in homes of patients he helped?" "The old crippled aunty, the widow with the epileptic child... " she went on. "All of them have house fellowships of thirty or so and our pastors and elders are going out to support and teach them." DHERSEC is led by Christians, with volunteers from the churches seeking out people in need, taking people to appointments, helping them through the system, and visiting. God is indeed alive and active and transforming lives as people grow to know and love him.

Concluding remarks

As a GP with a whole person approach, my aim is to help people towards reaching their full potential. Primary Health Care principles inform my philosophy, but the Christian idea of God calling each human being to live out the purpose he has for them is a fundamental premise. I am also keenly concerned for family members, especially devoted mothers who may sacrifice their own aspirations for the sake of the child/adult with disability. Also, the 'normal' sibling who may be a little neglected as a result. Sometimes people think that charity and development are opposite poles, but that is false. When Jesus said, "The poor will always be with you," (Matt 26:11) it was a statement of fact.

Caring for children and seeking their development is obvious, but some do not grow up. Sometimes the doctor is called to act like a co-parent, sibling or friend to a young adult with intellectual disability. They may enjoy seeing the maturation process and independence come say at 40 years. There are those for whom disaster strikes in middle age whose long adjustment to impairment

Sewing training

In the past 10 years more than 3,000 have been trained including many subsidised by DHERSEC. Trainer Purna (pictured right) is a single senior woman with a hip disability from birth. She has been president of DHERSEC and has been on the board since establishment. She works for the government Dept of Cottage Industries and also with Maiti Nepal and NGO advocating for and helping women and girls who are victims of domestic violence, trafficking and HIV. Her sewing courses are very popular. DHERSEC sponsors about 20% of candidates in every intake. Purna has been requested to go all over Nepal to organise women's groups and trainings and has been a strong advocate for people with disability in



the process. Although the majority of trainees are women, some men have gone on to establish tailoring businesses locally and in remote locations. The majority of women uses their skills with the family although many have become successful in business also. Although the focus is on gaining a skill, the development of the young women in socially and personally has been a most important output.

is a painful journey that the doctor can share. In our house we have early morning and late night phone calls from a dear pest of a lady who is both patient and church member. She so wants to be a family member. We received chocolate Easter bunnies "for mum and dad" from her. Demand for ear syringing every week has belatedly lead to realisation that her TM joints are osteoarthritic. Watch out around the shops – is she terrorising the place on her mobility scooter? Then there is the 53 year old alcoholic liver disease patient wanting to be parented. Mother entered residential aged care, but there is no place for someone his age. And there are the wounded personality disorder patients who have

been learning the hard way through many disasters. How do they access dialectical behaviour therapy in a town like this? Can we remain there for them after reception staff and other doctors have declared them "not welcome"? ●

by Dr Owen Lewis

Owen Lewis is a general practitioner in Port Pirie, SA. He and his wife Mary, (former doctor, now Anglican priest) were missionaries in Nepal. Owen coordinates Partners in International Medical Education in Australia and has been on numerous teaching trips to India and Uganda. He is International Adviser to DHERSEC, Nepal, the disabled people's organisation featured in this article.



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Loans and small business establishment

Two years ago, Binod did a course arranged by DHERSEC in mobile phones. His mother had recently died from lung cancer and father continues to have mental illness. The training has enable Binod to care for his father and younger brother and sister. Dhersec has been supporting their schooling. Binod established his phone maintenance business with the help of a Rs25000 loan. He repaid this within six months and took out a Rs50,000 loan to extend the shop. His business is thriving.



WRITERS & EDITORIAL HELP WANTED!



*Luke's Journal editorial team:
Dr Catherine Hollier, editor Dr Paul Mercer and Dr Winnie Chen.*

CMDFA publishes *Luke's Journal* three times a year. Do you have a passion for writing, editing or proofreading? Are you a creative big picture person who can help us brainstorm themes and articles? We would love to hear from you! The more people involved, the less workload for everyone! We need people in the following areas:

Brainstorming themes

- A big picture person to brainstorm ideas for topics of current interest and think through different facets of a topic. If you have a bit of a creative flair for catchy titles, that's a bonus!
- Someone with a good idea of contacts in terms of who is around, who might be available to write on different topics, or who has had different exposures in life. Ideally this would be a person in their 60s or 70s who has been in the fellowship for a while.

Commitment required is a minimum of two teleconferences per issue for 90 minutes each, usually in an evening. At 3 issues per year, this would amount to a maximum total time of 9 hours a year. The above do not have to take on a big load in terms of asking people to write, nor of proofing.

Writers and editors

- Someone with organisational skills to oversee or collate each issue. Ideally, we would have 3 people to do this, so that each is only responsible for one edition a year. That would make the journal much more sustainable over the long term. Committing to a 3-5 year term would be ideal.

- People to contact potential authors, and to follow up with them. There are simple checklists and templates to use in writing to people, with guidelines for when reminder emails need to be sent, and a tracking sheet to ensure we get bios and pictures with the articles.
- Anyone with proofing passion would be so appreciated.
- Anyone with a passion for writing/ ideas/ creativity would be a wonderful asset. For example, you could write a regular column on "Meet the Members", book reviews, histories, interviews, vales.

IT and website support

- People with IT and website skills for uploading issues, both as .pdfs and as individual articles on the website. Electronic versions of *Luke's Journal* is important at making the content accessible to a greater audience.

Thanks to all of you who write for *Luke's Journal* already, and a hearty encouragement to those of you who would like to be involved.

We look forward to hearing from you,

Paul, Catherine and Winnie

Luke's Journal



INSTRUCTIONS FOR CONTRIBUTORS

Members of CMDFA are invited to submit articles or letters to the editors for publication in **Luke's Journal**. Articles may or may not be on the advertised theme. Writers may wish to discuss their potential contribution with the editors or their state editorial representative before submitting.

Articles, letters, book reviews and lengthy news items should be submitted (preferably in electronic form) to the **editors** with a covering letter requesting their consideration for publication. Photos supplied should be high resolution JPEGs.

Advertisements and short news items should be submitted directly to the **sub-editor**. See page 2 for contact details.

My Story

God's provision for a doctor's long-term illness journey...

What follows is the major part of the story as to how I progressively became more unwell at work until I could no longer continue. I also include some of the reactions I experienced as a Christian, and the encouragements I found. My hope and prayer is that it may help someone, in some way, to cope with comparable circumstances.

2002 - 2004

In 2002, I was 50 and married to Catherine with three young children. I had been working at an essentially solo general practice for about 9 years when I was diagnosed with bronchiectasis and hypertension. This required hospitalisation on average three times per year for intravenous antibiotic treatment of the bronchiectasis.

In early 2003, investigations of ongoing nausea, weakness, malaise, fatigue and palpitations revealed an undetectable serum cortisol and low ACTH levels. My endocrinologist thought that the hypothalamic-pituitary-adrenal axis suppression was due to inhaled steroids I was taking for asthma, and that it would spontaneously resolve in some months. When it didn't, I began to pray earnestly that God would heal me of the adrenal insufficiency because I found it to be quite distressing and disabling. The symptoms were worsened by illness and also by the natural stress of working. However, months rolled into years with no improvement, until it became evident that God had chosen not to heal me. At that time, I was working full-time at the medical practice – ten to eleven sessions per week – but unable to find anyone to work part-time with me. Because of the worsening in my conditions I attempted to sell the medical practice. However, this proved fruitless, because it was a unit under lease in a shopping centre. So, in early 2004, I closed the practice.

2004-2012

I then began work with a group of general practitioners who opened a practice nearby. Here I worked part-time, six sessions per week, and initially this greatly eased the pressure I was under and my quality of life improved.

By 2012, however, my condition had deteriorated and, because of weakness and fatigue, I had begun to miss going to work and to church on Sundays. In April 2012, I experienced an episode of idiopathic multiple bilateral pulmonary emboli. The symptoms mimicked those of my bronchiectasis exacerbations, which meant that future

“When I look back on the many times I cried out to God not knowing how to continue or what to do, I see that my anxious concerns were for nothing.”

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similar symptoms had to be treated with caution. By late 2012, in view of an ongoing decline in my health and the difficulty I was having managing my weakness, anergia and fatigue at work despite using supra-physiological doses of Prednisone (10 mg or more), my endocrinologist advised me to stop work and take a total and permanent disability (TPD) payout. When Catherine and I calculated what living expenses would be required and to put our three children – then at high school – through University, by depending for five years on my income protection and then on the payout, we determined that we couldn't afford for me to cease work. So I renewed a decision I had made earlier, that I would aim to work until the age of 70, if God permitted.

January - July 2013

By 2013, it seemed as though I was contracting a virus every two weeks on average, despite wearing a face-mask. These would then magnify my adrenal

symptoms. Between the beginning of March 2013 and the end of July, I had five hospital admissions. As well, in the two or three months prior to July, I was missing about a day a week due to sickness. I often went to work feeling unwell with malaise and weakness and my symptoms would progressively worsen during the day. By the end of the day, I would experience breathlessness, chest tightness and pain. This limited my quality of life severely and was virtually beyond my ability to cope. Throughout this time, my medical judgment would come to the fore and insist that this situation could not continue.

After each admission, I was able to have a graduated return to work. However, by early July I simply could not work. A number of times I arranged for the receptionists to book patients in to see me but, on each occasion when the time came, I was too unwell to work.

July 2013 onwards

For some months before stopping work I had been feeling depressed and suffering insomnia. In July, I became deeply conflicted – wanting to work to provide for my family, yet simply unable to. And to my shame, I must confess that I was distrustful of God. So I was admitted to hospital yet again – this time to treat depression. During the admission, under the oversight of the psychiatrist treating me, I made the decision to discontinue work and to accept that I was no longer capable of it. This decision was based not just on my current state, but on the progressive decline in my health over eighteen months or more. It was also

during this time in hospital that God made Himself more precious to me. Richard Sibbes wrote: "God is nearest to us when we are in our greatest straits." That was my experience – I can truly say that this ultimately compensated for the suffering.

Because my income had ceased, and it took perhaps two months to receive the first payment from my income protection, we had no cash flow for a time. Since we were without any savings, we struggled to buy food, even groceries, and didn't know what to do. Then something startling happened. We started to receive cash donations. I was quite overcome by this, having not expected it at all. This continued until my income protection payments commenced. These people displayed fine acts of Christian kindness and love. It also reflected the immense care and love of God who had moved them to take this course of action. He who feeds the ravens did not fail to feed the Greenburys!

My income protection was accepted promptly on the basis of letters from two specialists, but the process of seeking a total and permanent disability payout was quite the opposite.

When the TPD insurance company asked to examine my bookings for some of the time before I had stopped work, I found that my policy stated that I had to have worked a minimum average of fifteen hours per week in the six months prior to ceasing work to be eligible for a payout. This came as a shock to me. Time spent outside

of appointments, such as arriving earlier and leaving later in order to peruse results, letters, etc. was not included. Fortunately – no, I should say providentially – my average was a little over sixteen hours!

In December, 2013, I received notification that I was required to be assessed by an independent medical examiner (IME) which was booked for six weeks' time. I contacted the AMA legal team who advised me that the IME could overturn the judgments of my specialists. The insurance company had earlier indicated that they expected me to deregister myself – which I had done in September 2013. So I faced the dismal prospect that the TPD payout might be denied to me, which would then cause my income protection to cease – and I was deregistered!

However, thankfully, the IME agreed with my doctors' judgment. Shortly afterwards, one of my specialists sent me to a neurologist to investigate ocular symptoms I was experiencing. The neurologist found, incidentally, that I had a mild cognitive impairment. Shortly after this I was granted the payout, some nine months after I had discontinued working. Though this seemed an extended period to me, some have told me that TPD payouts can take much longer to be approved.

Provision despite Anxiety

The period from July 2013 to April 2014 was a very dark time for me. Throughout it I suffered a lot of anxiety. I would continually ask for forgiveness for my lack of faith and

prayed for faith to endure. I would often remind myself of God's promises of earthly provision (Phil 4:19; Heb 13:5 and Matt 6:31-33). A further source of abiding comfort was the recollection of divine providence. When I look back on the many times I cried out to God not knowing how to continue or what to do, I see that my anxious concerns were for nothing. He always sorted out the problems. Though He gave me the answer "No" a number of times, I know that He does all things well and will ultimately direct all things for my family's and my welfare (Rom 8:28). Finally, communion with God and Christ would often bring me a deep-seated joy and comfort in the midst of outward turmoil.

From 2014 onwards the frequency of infections gradually reduced. Now, though I cannot work, I have a new-found quality of life. And God has enabled us to manage financially. In view of all this, I believe I can gratefully acknowledge with Samuel, "Up to this point the LORD has helped us!" (1Sam 7:12). ●

by Dr James Greenbury

Jim worked briefly at the Royal Brisbane Hospital before spending 3 ½ years as medical superintendent at Richmond in Queensland. After this he worked for eight years as a GP at Dalby. After returning to Brisbane, he worked at practices in Carina and Wellington Point. During this time he completed a Bachelor of Theology degree. He retired from medicine, due to ill health, in 2013. Jim is married to Catherine and they have 3 adult children. His hobbies include reading, writing and chess. They attend a Presbyterian church at Annerley.



SO...

TELL ME EVERYTHING
YOU TOLD THE NURSE
5 MINUTES AGO...

Laughter is the Best Medicine

We are seeking contributions for *Luke's Journal* of funny stories, jokes, cartoons and anecdotes, for the first issue in 2019 – theme: "Laughter is the Best Medicine".

Send your submissions to Catherine Hollier (editor):
LukesJournalCMDFA@gmail.com

The next issues of *Luke's Journal* will cover the themes:
"Hot Topics in Ethics" (copy due 30 August 2018); and
"Laughter is the Best Medicine" (copy due by 30 January 2019).

Disempowering Support

When interacting with patients or clients with disabilities, health professionals should be respectful, empowering and dignifying. The contrast can be detrimental. My experience with a disability support worker was disempowering.

I'm a performance poet, public speaker and advocate. I work for CBM Australia, who work to empower people with disabilities who live in the poorest countries. I have cerebral palsy. As part of my work I've travelled a number of times from Melbourne to Canberra to attend Micah Australia's Voices for Justice. Voices for Justice is a gathering of Christians from across Australia, lobbying the government to increase the Australian Aid budget.

A couple of years ago there wasn't a colleague available to support me as I travelled to Canberra. It was arranged through an agency for a support worker to assist me. When I met her at the airport in Canberra I offered my hand for her to shake. Instead she held my hand. When we got to the car I told her that if she holds her arms out, palms up, I can use them to balance and get myself into the car, bearing my own weight. She began to do that, but then she wrapped her arms around my waist. I was no longer able to bear my own weight. I learnt it was futile to state the support I wanted, and didn't want. She often referred to me as 'Darling'.

I performed a poem during a church service that evening. While on stage, I choose to leave my walker or wheelchair behind. But I couldn't trust her to assist me onto the stage in a dignified way. I remained in my wheelchair.

In the hotel that evening I told her I didn't need help dressing, showering or getting into bed. A few times I was



Stevie Wills,
Photo: CBM

"I was given a role to play by the person I depended on. The role of 'child', or 'needing mothering'. It was easier to play the role then to fight to be the mutual adult."

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asked if I was sure. I said I had a cup that has a lid. "Oohhh fancy" she said. My cups are not fancy. They enable my independence.

The following day she arrived at the apartment earlier than we had agreed. Having yet to finish preparing myself for the day, I went to the bathroom. I asked her to shut the door while she waited outside. Killing time at the café' in Parliament House I told her that I don't like being in my wheelchair

all day. At home I mostly use my walking frame. She said "I should have rubbed some cream on your bottom". I felt incredibly uncomfortable. She assumed her entry into my privacy without the need for caution. I counted down the hours before I could get on the plane. I wanted to get away from her.

She expressed her admiration of my poetry performance. She said I was one of the most intelligent people she's ever met. Not long after that she questioned, for a few minutes, my decision not to take my drink bottle with me as I met with a politician. Feeling so uncomfortable I wasn't present in mind during the political engagements. As I departed for Melbourne, she kissed me on the cheek.

Discomfort remained with me for weeks. She had entered herself into a private space, close to my soul. I couldn't push her out of that space, away from me. I felt grime within.

DISABLING by Stevie Wills

I regretted that I didn't speak up for myself whilst in Canberra. Over time I realised there were several reasons why I didn't. I assumed people working in disability services would respect people with disabilities. My experience was unexpected. My energy was limited, and hence directed to the poetry performances and political engagements. I didn't know the support worker, or how she'd react if I spoke up for myself. I depended on her, thus kept the peace with her. Assistance is responded to by gratitude. Feeling violated, I withdrew further. It was stressful and embarrassing to tell my colleagues of my experience, despite their respect, professionalism and concern. I don't talk to my work colleagues about my bottom. It's difficult to make a complaint against someone who considered herself helpful. I imagine it would be painful to realise she had violated her client.

After those two days with the support worker, I returned home to my life of empowerment, dignity and respect. I was supported during my distress and as I processed the experience, and made a complaint. I will never see the woman again. The impact of my experience has been long term. Many people with disabilities don't have the resources and support that I have to deal with my experience. Some can't, or choose not to complain, enduring similar experiences many times over. Some are physically violated.

"Her assertive assistance undermined my autonomy."

.....

I was given a role to play by the person I depended on. The role of 'child', or 'needing mothering'. It was easier to play the role than to fight to be the mutual adult. I had limited energy. I kept the peace with her. Though assertive, I quickly became passive. I was parented, thus evoked to respond from my inner child. Her assertive assistance undermined my autonomy. Her manner towards me defied the values of my work and of Voices for Justice. I was surrounded by people who valued empowerment and dignity. With my inner resources diminished, and focused on the political tasks at hand, I didn't reach out to anyone. If a support worker doubted the competency of a performance poet and political lobbyist, she would doubt the competency of many of her clients. People with disabilities who are continually parented and undermined may be conditioned to play childlike, passive roles. ●

by Stevie Wills

Poet, public speaker and advocate.

Published with permission. This article was first published at <http://www.ethos.org.au/online-resources/Blog/strength-in-weakness>.

I arrived a professional
an activist, political
I was mothered.

Recognised was my intelligence
yet in question was my competence
to know what was needed
to name the support I needed
met with an overriding
taking over.

As I recognised
it futile
to specify
the support I'd like
withdrawing, I declined
to specify
playing into the role
I was expected to play.

With the word 'darling'
tone of voice matching
I was set in place
not to speak horizontally to you
but diagonally up to you.

My privacy I'd always assumed
Your entry within, you assumed
in a statement
not a question of permission
charging shock through my system
by paralysis tailed
I was unable to communicate
to my peers that I wasn't okay.
Left with a grime that doesn't wash away
with the falling of hot water
scented soap lathers
only with the passing of time
the seeking of God
for his cleansing.

To mother
calls for a response from the inner child
rather than from the mutual adult.
To mother
I wonder
whose needs this fulfils.
To extend a role of support
beyond that needed
beyond that wanted
beyond that requested
other than requested
is disabling
disempowering
calls for surrender
nurtures passivity
a sense of powerlessness
smothers autonomy
a sense of control
choice
ownership of self
of flesh
flesh, so intertwined with soul.
Ownership, the granting of permission
rather than submission
to in regard to one's self
someone else's decisions.

Parkinson's Disease

– A disability or a blessing? (or both?)

Diseases and disabilities are things that happen to “patients”, that is to say, “other people”. They do not happen to doctors, especially not to me.

Over the past decade this optimistic fantasy has been gradually replaced by reality. From the age of 30 to 60 I did not notice any ageing. My height, weight, energy and fitness seemed very stable. Then I began to notice small signs of deterioration. Brushing my teeth became slightly clumsy. My handwriting was less fluent and I could no longer sign my name automatically, without thought. I had surgery on my right hand to relieve nerve entrapment in Guyon's Canal. Instead of the expected restoration of dexterity, the clumsiness in my right hand continued to worsen. I developed a slight limp in my right foot. When she noticed some twitching, my wife, an experienced GP, even wondered about motor neurone disease.

After appropriate investigations my neurologist announced, “you have a progressive extrapyramidal degenerative condition, probably Parkinson's disease”.

No! I do not want that! Is this some kind of cosmic joke?

For many years I had used the following question in tutorials with medical students. “If you could choose the way you will die, would you prefer to die suddenly and unexpectedly, or slowly and predictably?” On average, two thirds prefer a sudden death. I always said I wanted a slow death (with no symptoms, and expert care by a palliative care specialist), so that I had plenty of time to prepare. I could almost hear God chuckling, “Would 10 years be long enough? 15 years?”

That was 11 years ago. I do indeed have Parkinson's disease, but it has progressed very slowly. I can still safely drive my car and use my two beloved chainsaws (to my neurologist's horror).

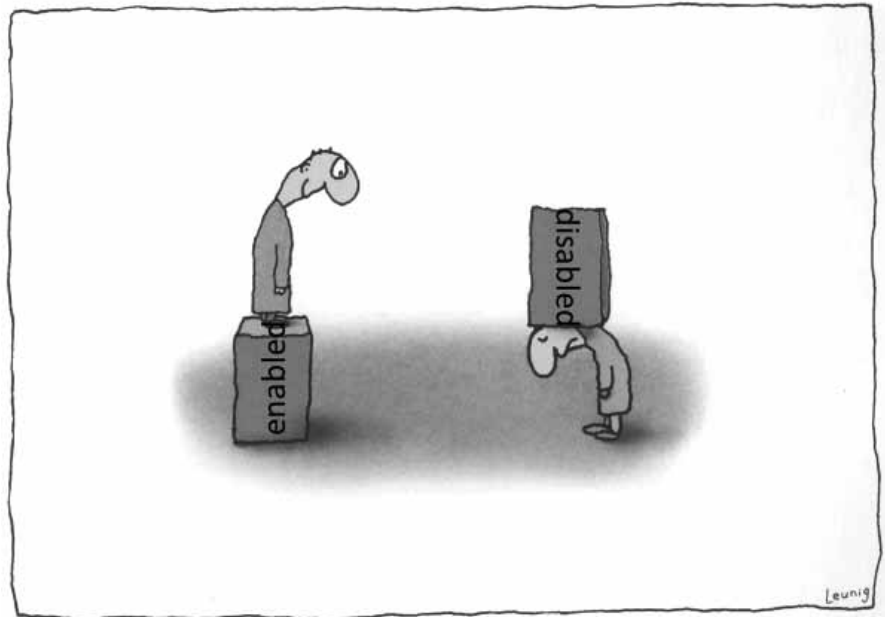


Image courtesy of Michael Leunig

On waking I am rather stiff (rigidity) and sluggish (bradykinesia) but so far, I have no tremor. I have not fallen, though I might agree that I am ‘a falls risk’. From my perspective, my biggest handicap is a soft voice and slightly mumbling speech (hypophonia and dysarthria). An hour after my first morning dose of Madopar, my nervous system function is almost normal.

Elizabeth Kubler Ross, the famous pioneer of studying death and dying, said “It's only when we truly know and understand that we have a limited time on earth – and that we have no way of knowing when our time is up, we will then begin to live each day to the fullest, as if it was the only one we had”.¹

I think I have reached that point.

In his book, *Personhood and Presence*², Scottish hospital chaplain, Ewan Kelly, describes an exercise he uses to help health professionals consider their mortality. He reads Roger McGough's poem, *A Youngman's Death*³, then asks participants to consider what for them would be a good death: “In order to facilitate a discussion about fears around death and dying, I then ask them what death they would not like and

why”. Ewan concludes, “An awareness of our life being a gift of a limited time-scale rather than a right to ongoing health and longevity may enable us to embrace life more fully in the present and all that each moment may offer us.”

At present, the Western Australian parliament has a joint committee to consider end-of-life issues. Last week I appeared before the committee. The nature and purpose of suffering was of great interest to the committee. In a secular, materialistic culture people struggle to find meaning in suffering.

Disability, illness, divorce, imprisonment, employment and grief are all experiences of loss. They can all produce suffering. But, as concentration camp survivor, Jewish neurologist/psychiatrist Viktor Frankl says, “In all of these terrible circumstances, we still have a choice about the way we

Strength from a wound?



Soren Kierkegaard:
“With the help of the thorn in my foot, I spring higher than anyone with sound feet”
Danish philosopher and theologian
1813-1855

respond. We may respond with anger, bitterness and revenge, or with acceptance and forgiveness" (paraphrased⁴).

Reflecting on decades in Siberian prison camps, the Russian Nobel Prize winner Alexander Solzhenitsyn says, "Prison causes the profound rebirth of a human being... *Your soul, which formerly was dry, now ripens from suffering...* And that is why I turn back to the years of my imprisonment and say, sometimes to the astonishment of those about me: "Bless you, *prison!*..."⁵

My Parkinson's disease will undoubtedly progress. Every year I will experience more loss, and will retain the freedom to choose my response. I am learning to follow Solzhenitsyn's example, and say, "Bless you Parkinson's Disease." Or, in the metaphor of Leunig's delightful cartoon, I can choose to relabel my 'disabled' badge to 'enabled'. ●

by Dr Doug Bridge

Doug is married with three sons. After training as a general physician and in tropical medicine, he lived for two years in a Bangladeshi village. He helped pioneer the development of Palliative Care in Australia and Asia. He was the Head of the Palliative Care Service at Royal Perth Hospital from 1993-2013. His special interest is the psychospiritual challenges of dying. His two-day "Spirituality Workshop" is being adopted by the RACP for use by palliative medicine advanced trainees.



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LET ME DIE A YOUNG MAN'S DEATH

by Roger McGough

Let me die a youngman's death
not a clean and inbetween
the sheets holywater death
not a famous-last-words
peaceful out of breath death

When I'm 73
and in constant good tumour
may I be mown down at dawn
by a bright red sports car
on my way home
from an allnight party

Or when I'm 91
with silver hair
and sitting in a barber's chair
may rival gangsters
with hamfisted tommyguns burst in
and give me a short back and insides

Or when I'm 104
and banned from the Cavern
may my mistress
catching me in bed with her daughter
and fearing for her son
cut me up into little pieces
and throw away every piece but one

Let me die a youngman's death
not a free from sin tiptoe in
candle wax and waning death
not a curtains drawn by angels borne
'what a nice way to go' death

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TABOR

Strength in Weakness

Elena Down's story

If you had told me as a timid twelve-year-old, just fitted with hearing aids, that one day I would celebrate my disability, I would have thought you were seriously deluded.

But bringing me from mourning to celebration is a great act of love that a wise God has worked into my journey with him so far.

So how did I reach this point – what has happened since that day when I was so devastated and uncertain about the future because of my deafness?

Let me tell you something of my journey by reflecting on three questions I think I've been asking all my life:

- Do we see disability as punishment or gift?
- Do we see disability as weakness or strength?
- Do we see people with a disability as those who need to be ministered 'to' or as those 'with' whom we can minister and 'from' whom we can learn?

Early church – acceptance, love, enabling

Thanks to my parents and grandparents, I had the privilege of growing up surrounded by Christian values. It laid a firm foundation on which I've built my life.

My early experiences of church were overwhelmingly positive. I was nurtured and loved in the company of people of all ages, and came to understand Jesus' love for me through the love shared among the congregation.

There was a family at my church who had three children, one of whom had Down syndrome. They learned so much through that experience that they chose to adopt another child



Elena Down at Luke14 National Launch. Photo: CBM.

with Down syndrome. They were inspirational people of great love.

Another lady at our church lost her hearing and her speech as a result of a stroke – her family had to find new ways to communicate with her. They and others in the church committed to learning sign language, and each week a group of people came to their home for lessons from a local deaf person. This helped the family stay connected to the church.

“We have the vital role of bearing witness to God's values and of being vibrant communities of welcome, encouragement and justice.”

.....

Some churches seem to have the idea that you need to be 'called' to do 'disability ministry'. I always thought that a bit strange – aren't we called to love everyone and bear one another's burdens? We have the vital role of bearing witness to God's values and of being vibrant communities of welcome, encouragement and justice.

My early experiences taught me that church communities, when they are inclusive, can be a source of immense

encouragement – to people with disability, their families and the wider community.

Praying for 'Healing' – a punishment or a gift?

At various points in my life, some people have felt the best response to my disability has been to pray that I would be healed.

There is nothing inherently bad about praying for healing. God asks us to pray big prayers, and, indeed, Jesus healed a deaf man. (There is a joke in the deaf community that Jesus did this by touching the man's ears, then his mouth, thus giving him sign language – it's the sign for 'deaf'.)

I'm sure that some people have thought their prayers for me were not answered – after all, I'm still deaf.

Some people at various points have told me I simply lacked faith, and if I only had more faith, I would be healed. I'll leave God to measure my faith, knowing that his ways are higher than mine.

In my own situation I feel God has said, 'Elena, this is how I made you,

and I don't make mistakes – “my grace is sufficient for you, for my power is made perfect in weakness”. (2 Cor 12:9) Therefore, with Paul I will boast about my weakness, that God's power might work through me – and so that the glory goes to him. After all, it's often my deafness that God has used to conform me more to the pattern of his Son:

- Experiencing barriers gives me great compassion and empathy for the struggles of others.

- Experiencing rejection and discrimination makes me stand up for God's values of equity and justice.
- Facing daily exasperating situations allows me to develop patience, perseverance and self-control.
- Knowing my own limitations means I am more aware of my need for God's strength.

God has worked not *despite*, but rather *through*, my disability. He has allowed me to use my disability in both my public and professional life, and in ministry.

Leadership and equipping – seeing the giftedness

I owe a lot to people who saw my disability as a gift and nurtured me, allowing me to ask hard questions, struggle with God and grow in my faith. I've been able to use this to help others struggling with similar questions. Sometimes you need to walk the road to earn the right to speak.

But for a long time I felt I had to 'rise above' my disability, to succeed 'despite' it.

I'm so grateful to the mentor who, when asked to find me an overseas volunteer placement, sent me to a deaf women's project in India. I'd like to say I was elated, but in fact I was indignant! Just because I had a hearing impairment didn't mean that I should go and work with deaf people. I had lots of skills to offer. I'd done all this training that could be put to use. But in her quiet wisdom, she saw my deafness as a gift that would particularly benefit this project.

I learned a lot in India – about myself, my values and God's values. I experienced material poverty, but a wealth of friendship and joy – particularly among the deaf believers. I was loved and accepted by deaf women because I was 'one of them'. I was able to share about my faith and what God meant to me. For the first time, I could see that my deafness was something that could open doors and enable other people to know God. I could see it was part of me He loved.

And so I responded next to a call from God to go to China to work with the deaf, of whom there are some 90 million – most of whom have no opportunity to know God.

It was possibly the scariest step I have taken, and also the most amazing two years of my life. What people said would be impossible, God made possible. I mastered not only written and spoken Chinese, but also several dialects of sign language. I mentored deaf uni students, helped set up a support group for parents of deaf kids

“For the first time, I could see that my deafness was something that could open doors and enable other people to know God. I could see it was part of me He loved.”

.....

and started sign language classes with a local deaf student. Through it all I had amazing opportunities to share my faith and see people come to know God – not only deaf people, but several language teachers moved by the values that drove my life.

It's a joy to me that seeds I planted during that time have borne fruit with a deaf church now established in that city. I'm reminded again that God's word goes out – indeed, sometimes in sign language – and it never returns to him empty.

Learning from the giftedness of others

Looking back I realise I've learned so much from my friends with disability throughout my life.

I've been challenged by the unaffected, honest and sincere love for God of friends with intellectual disability. We often make our faith so complicated when all God wants is a humble and faithful heart that responds to him.

During college I met Lisette, who is blind. I'll never forget the stack of

Braille chapters of her Bible piled next to her desk! External appearances didn't matter to her. She reminded me that God looks beyond the surface.

Some of the most powerful teaching I received was from a preacher who had been born deaf and had become blind. He could still sign to communicate with others but needed tactile sign to receive communication. He was one of the most intelligent, positive and profoundly insightful people I've met. Perhaps it was the hours of time to sit and reflect, uncluttered by the sights and sounds that so easily distract us.

A friend of mine who lives with depression shared with me his firm belief in the truth that God loved him, regardless of his subjective experience or feelings. He had an unwavering trust that 'nothing can separate us' from that love.

My faith would have been less if I had not met these people. And yet I look in churches and don't see people with disability there.

So what's the role of churches?

I believe we *impoverish* the church and rob ourselves of all that God can teach us when we fail to fully include people with a disability.

Jesus demonstrated an inclusiveness and concern for people with disability, and told parables to show their place in the kingdom of God. Church communities should be marked by similar commitments.

I know I have at times felt excluded when there is no audio loop or interpreter, when people bow their heads too low so I can't lip read their prayers, when there is a preoccupation with music and singing which I can't easily participate in, or if conversation in home groups is too fast. I know many older people stop attending church when their hearing starts to fail. We all miss out when this happens.

My sneaking suspicion is that most churches don't set out to intentionally exclude people with a disability; they just never really stop to consider the barriers that prevent them participating.

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STRENGTH IN WEAKNESS

The key is our attitude – having a motivation of justice, love and equal concern ('... so that there should be no division in the body, but that its parts should have *equal concern* for each other' – 1 Corinthians 12:25). People with a disability want to be – deserve to be – included in an accepting and welcoming community that welcomes their gifts and talents. Making sure we are inclusive is simply a part of the great commandment to 'love one another'.

Finally, to believers who know disability first-hand

For those who have faced exclusion and frustration because of disability, can I share with you the deepest treasure of wisdom garnered over my life? My true inner strength comes from knowing that God is the truest

and most trustworthy 'friend of my heart':

He knows all my thoughts, knows all my weaknesses, fears, hurts and disappointments, and knows my anger, even rage, at injustice when people are being treated unfairly and excluded.

He even knows I've sometimes felt angry at him for my disability during the tough times.

And yet (here's the best bit) in the Bible He has promised me that He loves and accepts me, just as I am – nothing more, nothing less.

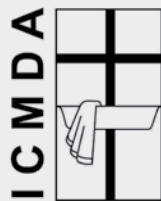
If God is for me, who can possibly be against me? If God was prepared to go to such great lengths to draw me

to Himself, won't He also be able to help me through whatever difficulties and obstacles may come my way? This is the truth that has brought me enormous freedom and the inner strength to see me through whatever challenges life throws at me. May this truth be yours as well. ●

by Elena Down

Elena was an eloquent and accomplished advocate for people with disabilities, particularly deaf people. She worked as Disability Inclusion Advisor for CBM Australia. During her time at AusAID she assisted in the development of Australia's first Disability Inclusive Development Policy. Elena passed away on 18 March 2017, aged 44.

This article was first published in Equip, Issue 17, June 2013, 8-9, at <http://www.ethos.org.au/online-resources/Blog/strength-in-weakness>.



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VALE

Alan Donald Hewson

1927 ~ 2017

Alan Donald Hewson was born in 1927 in Lisarow, NSW. He graduated in Medicine with Honours from the University of Sydney in 1952 and had three years general training as a resident at Royal Newcastle Hospital (RNH). Then followed two years as a registrar in Obstetrics and Gynaecology at Royal Hobart and two further years at Oxford with Sir John Stallworthy (after obtaining his MRCOG – working as Senior registrar and tutor in Obstetrics).

He met his wife Pia in fourth year medicine. They married at the end of the course and did three years together in RNH as residents. They came from such different backgrounds: Pia, a post-war immigrant from Europe, and he, a self-proclaimed poor child from outside Gosford. They had a meeting of hearts and minds – a truly Australian relationship. He was so proud that she was the first female resident at RNH and beat all the males in her degree.

They had three children, Edward, Vicki and Lynda. Later, Pia tragically passed away from cancer.

Alan began private practice in Newcastle in 1958, with Honorary appointments at Royal Newcastle, the Mater Misericordiae and Western Suburbs hospitals as well as appointments at most of the private hospitals as they developed over the years. He worked with his great friend and mentor, Dr Jack Elliott, for many years. Jack was his senior at RNH and encouraged Alan to consider O&G because the patients appreciate your efforts – if the child is brilliant, it's because of your delivery – and they are mostly grateful.

As time went on, Alan decided he needed more surgical skills so he obtained the FRCS Ed. in 1966, the FRACS in 1980, was a foundation member of the RACOG in 1979 and was



awarded an Honorary Doctorate from the University of Newcastle in 1990.

He also married Patricia and they had a long and very loving relationship. Pat tried to keep his many interests in some sort of order at home. Alan's email was Pat's email address. She was such a warm and gracious hostess to the many visiting dignitaries and local medical fraternity. She was his rock that supported him in his later years.

He served for 11 years on the Council of the RACOG from 1981, chaired its Education committee for 6 years, was Secretary for 3 years and played a leading role in the development of its ground-breaking obligatory Continuing Education programme, for which he was awarded the Gold Medal of the College in 1989.

He was also heavily involved in the development of the new Medical School at Newcastle which opened in 1978. He had been on the teaching faculty since and was appointed as Conjoint Professor in 2000.

He chaired the medical planning committee for the John Hunter teaching hospital, served on the Board of the Greater Newcastle Area Health for 3 years and was the first Director of Gynaecology at John Hunter Hospital.

He was a founding member of the Hunter Postgraduate Medical Institute in 1979, was on the Board since, and was President from 1981-1983. He was also President of the Postgraduate Federation in Medicine for 5 years, and had been invited Professor and lecturer to many centres in Australia and overseas.

Although primarily a clinician, he has contributed a wide range of articles to the literature on his own discipline and on his special interest in medical education. His O&G interests have been perinatal mortality, vaginal surgery, genito-urinary fistulae and third world medicine. He was made a member of the Order of Australia in 1992.

Alan seemed like he was going to live forever. I met him as a medical student in 1976. He interviewed me in 1982 for a job in Western Suburbs Hospital and we worked together for the whole of my career. I remember calling him in often to assist with a complicated delivery at 2 or 3 am. He always arrived in a suit and tie. He was a very generous teacher and a dedicated clinician. His passion for medical education ran deep.

Retirement was a figure of speech for Alan. He decided to do a PhD in the medical history of obstetrics, spanning more than 60 years. He then converted this into a book, *Tragedy, Trials and Triumphs: Obstetrics and Gynaecology in Australia in the Twentieth Century* (Rosenberg Publishing, Pty Ltd), which was launched shortly after his death on 19th August, 2017, aged 90 years. A book review can be found on page 61. ●

by Dr Milton Sales

Milton is a GP in Newcastle who presented this vale as Program Committee Chair of the Hunter Postgraduate Medical Institute.

Persistent Pain in Children

"Pain is whatever the experiencing child says it is, existing whenever the experiencing child says it does."¹
– Margo McCaffery, 1989

Definitions

The International Association for the Study of Pain defines pain as an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.² Herein lies part of the challenge as we try and distinguish between the emotional and physical aspects of pain and also take into account its subjectivity. It is suggested a holistic approach to pain is required where we consider both the emotional and physical together. It can be more helpful to focus on the mind-body connection or interaction, rather than have a dualistic approach to the mind and body. The dualistic approach, otherwise known as the mind-body problem, was closely associated with the thought of Rene Descartes in 1641.³

Nociception refers to the activation of pain pathways per se, without regard to its emotional, social or cultural significance. Suffering can relate to the broader unpleasant psychological or existential experience associated with pain, as well as other attributes of the illness (e.g. weight loss or difficult to manage wounds). This was a feature of Dame Cicely Saunders early work in palliative care with adults, which included an articulation of the relationship between physical and emotional suffering.⁴ This reached expression in the concept of "total pain" which includes physical symptoms, mental distress, social problems, emotional difficulties and existential/spiritual challenges. "Pain demands the same analysis and consideration as an illness itself. It is the syndromes of pain rather than the syndromes of disease with which we are concerned."⁵

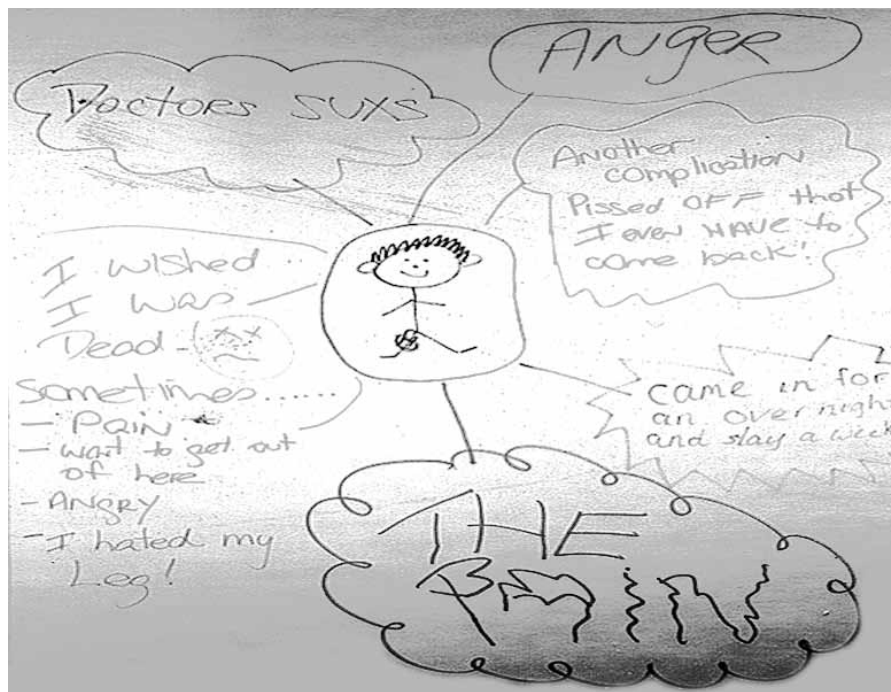


Figure 1 – Drawing by a Child Showing Concepts of Pain and Suffering

Assessment of Pain in Children

It is important to remember that patient report (or parent proxy when the child is unable to communicate) is the gold standard to make an assessment of the presence and severity of pain. An inability to communicate verbally does not negate the possibility that an individual is experiencing pain.

This is particularly relevant to neonates and infants, as well as those with cognitive impairment. Before the 1970s, the medical literature is essentially devoid of any formal reviews of research specifically addressing the management of pain in children.⁶ Work by Eland identified both significant undertreatment and enormous discrepancies in child and adult prescribing practices for pain management.⁷ Despite this sentinel research, it took some time for children to receive adequate analgesia. In the 1980s, multidisciplinary pain teams became increasingly prominent and could address the transdisciplinary

nature of pain and develop theoretical models that were not limited by discipline. Such a multi-disciplinary pain clinic was set up at The Children's Hospital at Westmead, Sydney, ~1989 by Drs Henry Kilham and John Keneally. An audit of patients presenting to a similar pain clinic at Royal Children's Hospital, Melbourne, from 1998 – 2000 looked at the treatment of 207 patients and showed a mean age of 13.1 years⁸. Similar clinics have been more recently established in Perth (2013) and Brisbane (2014). There is hope a similar clinic will be established in South Australia in the near future.

Development of assessment techniques for children of all ages that allowed interventions to be more effectively measured have been very helpful. Examples of assessment tools include the FLACC (which quantifies behavioural observation of pain such as facial expression, limb, activity, cry and consolability) for non-verbal children aged less than 4 years.⁹ Other examples include the Faces scale (appropriate for

children aged from 4 to 7 years with normal development) and the “Non-communicating children’s pain check list” for those children with cognitive impairment or severe disability.¹⁰

Causes of Pain in Children

An audit of 207 patients who attend a children’s pain clinic in Melbourne found three-quarters of the patients were female and 29 % lived in rural

paediatrics, psychiatry, psychology (and other psychosocial expertise such as social work), physiotherapy, occupational therapy, nursing and expressive therapies (such as music or art therapy) all have an important role in the management of persistent pain. When explaining the cause of pain to a child and their parents, it is always important to validate the child’s pain experience as very real. It is possible to conceptualise the management of pain in children by the 3Ps (pharmacology, physical and psychological therapy).



Figure 2 – Faces Pain Scale^{9a}

Instructions to the child are: These faces show how much something can hurt. This face (point to the left most face) shows no pain or hurt. The faces show more and more pain (point to each from the left to right) up to this one (point to the right-most face) – it shows very much pain. Point to the face that shows how much you hurt right now.

Do not use words like “happy” or sad” This scale is intended to measure how children feel inside, not how their face looks. Numbers are not shown to children; they are only shown here for reference. The instructions for administration are currently available in 12 languages.

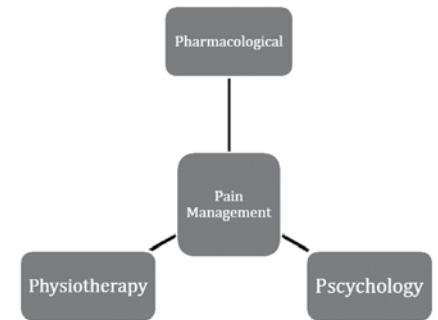


Figure 4 – The 3P's of Pain Management.

Many children with persistent pain have significant functional disability (school absenteeism, sleep disruption, an inability to perform sport and social disruption/ isolation). Importantly, functional improvement could be achieved using an interdisciplinary approach to pain management in these children. This can sometimes be summarised as the 4S's (Sleep, School, Social and Sport). If an assessment of spirituality (features of hope and suffering and the community that is important to the child) is included then this becomes 5S's. Mood disturbance (depression or anxiety) are also important to check for. There is a bidirectional relationship between pain and mood. Pain can lead to worry and sadness in children. At the same time, underlying depression or anxiety in a child can manifest as pain (and other symptoms such as nausea or poor balance) on occasion.

locations. Concomitant medical conditions were present in about half of the patients (cerebral palsy and cancer being the most common). Other medical conditions associated with pain in children include juvenile arthritis (and other rheumatological conditions), neurological conditions (both neurodegenerative and neuromuscular) and metabolic conditions. There are also pain syndromes which are not associated with an underlying medical condition. These include chronic daily headache and recurrent abdominal pain. Musculoskeletal pain also occurs in children. Complex regional pain syndrome (CRPS) was diagnosed in 44 of 207 patients (21%) at the Melbourne clinic. A recent study at The Children’s Hospital at Westmead, Sydney, found approximately 20 % of 544 patients who attended a multidisciplinary pain clinic had a developmental disability.¹¹ Multi-system comorbidities and emotional disorders were also prominent in this group of children. ¹¹

Pharmacological

The World Health Organisation (WHO) have developed guidelines for the management of persistent pain in children. This includes a 2-step ladder for managing pain.¹² Simple analgesia can be used at first and this includes paracetamol and non-steroidal anti-inflammatory medicines (NSAID). Ibuprofen is a commonly-administered NSAID to children in Australia. Adjuvant analgesics are any medications whose primary role is for a purpose other than pain relief, but which are used in combination with an analgesic to control pain. An adjuvant medication can be used for neuropathic pain and also more complex forms of pain. In children, the commonly prescribed adjuvant analgesics include amitriptyline and gabapentin. The WHO observe that we have limited research (such as randomised controlled trials) into these therapies, including adjuvant analgesics. The role of opioids in children with persistent pain requires clinical judgement and practical wisdom. Current practice is that opioids are generally not helpful in persistent pain of children. However, they do have a role in cancer pain, and when there is serious illness or severe physical disability.¹³ Opioids

continued over page >>>



Figure 3 – The 5S's of Assessment of Persistent Pain in Children

Management Strategies

A bio-psycho-social-spiritual approach is required for both the comprehensive assessment and interdisciplinary management of pain in children. The foundation for such an approach includes a thorough, holistic and interdisciplinary assessment. The disciplines of pain medicine, general

PERSISTANT PAIN IN CHILDREN

are particularly important in providing analgesia when end of life care is required.

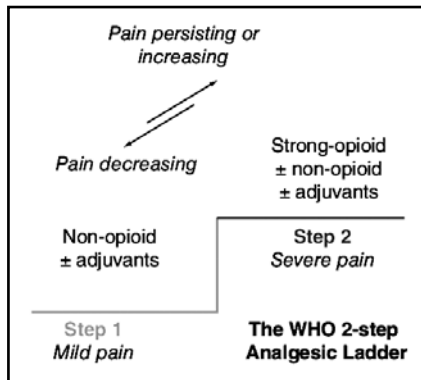


Figure 5 – WHO 2 step ladder for managing pain in children. A non-opioid is a simple analgesic such as paracetamol or an NSAID (e.g. ibuprofen).

Physical Therapy

While the management of acute pain is usually associated with rest (e.g. splinting of a fracture or sprain, and being nil by mouth at the time of appendicitis), the management of persistent pain usually responds to gradual and graded physical activity. Physiotherapists can play an important role in empowering parents and family to regain activity and movement in the context of pain. Pacing (or gradually increasing activity and not overdoing it) is also important in this context. Hydrotherapy, where available, can be very helpful for musculoskeletal pain in children (similar to adults). Occupational therapists can assist with providing strategies around relaxation, activities of daily living, goal setting and desensitisation. Desensitisation is often helpful when there is hypersensitivity and allodynia. Hypersensitivity and allodynia frequently occur in complex regional pain syndrome and other forms of neuropathic pain. Allodynia can be so severe that the child may not be able to use that limb (e.g. they may not tolerate wearing socks or having sheets on their feet at night).

Psychological

Psychological therapies are also important in the management of pain. When introducing the importance of psychological therapy to children and their parents, it is important that you do not convey the message

that the pain is not real or “all in your head”. In this context, it is helpful for psychologists and psychiatrists to see patients and families as part of the initial assessment process, as the emotional component of care and management is seen as an integral and upfront part of the holistic management process. This is a different model to where a patient may first see a doctor, then physiotherapist and they are then finally referred to a psychologist (giving the patient the impression that this is a last resort in managing the pain, and the problem is no longer a physical one).

Some helpful ways that psychological strategies can be introduced into the management of a child with persistent pain include:

- Building rapport with the family by taking time to listen to the child's and parent's narrative of their pain (this can take some time), and finding out the interests of the child and family. Some families may have a strong faith or rely on prayer for healing. The child may be involved in a church youth group. It can be helpful to self-disclose one's own faith in such a situation to help build rapport. However, this always needs to be carefully considered, particularly when there are significant mental health issues, or if the treatment you are advocating in the best interests of the child is contrary to what the parents are hoping for.
- Validating the pain as real for that child and family.
- Perhaps explaining that there has been no underlying tissue damage found to explain the pain (sometimes this can be referred to as medically unexplained pain). This can then be reframed in a positive way (e.g. the MRI scan found you do not have a brain tumour, or the bone scan found that there is not a serious infection in your bones). Rather than using the term medically unexplained, we could use the alternate phrase “medically-unexplored”. By using this term,

I am advocating that there may be a need for significant listening over time to fully understand the pain and its meaning and significance (usually requiring an interdisciplinary team).

- Explaining that pain can affect a child's mood and feelings, and this is one reason why we are keen to involve psychological medicine.
- Explaining the mind-body interactions in the experience of pain, and hence its potential management.
- Explaining that many non-drug strategies are important in managing pain and psychologists have much of the expertise in teaching children and parents these strategies (e.g. distraction and guided imagery). More sophisticated strategies of pain management may include cognitive behavioural therapy (CBT) and acceptance and commitment therapy (ACT).
- There are many phone and electronic tablet “Apps” which can help with pain management (pain diaries, as well as other strategies to manage pain including relaxation and distraction). However, there can be a small number of children who may have an internet addiction and are constantly using their electronic devices under the guise that they are needing to do this to manage their pain.¹⁴
- Often it is important to emphasise a functional approach to managing the pain. The child needs to start doing the things that the pain has been stopping them doing (e.g. attending school, working on a good sleep regime, physical activity) and the pain will then gradually resolve. Some children and parents may have the expectation that the pain needs to be resolved by finding a specific diagnosis or with medication management, before therapy on function can be instigated. A more usual pattern is for restoration of function (e.g.



activity, walking without aids, better sleep, better mood and school attendance) and then the pain will gradually subside.

- Adolescents will benefit from adopting an approach of self-management of their pain. Use of peer groups (and sometimes online resources) can be helpful in this context. Painbytes is an excellent resource developed for adolescents by the New South Wales Agency for Clinical Innovation.
- Be open and non-judgemental to complementary and alternative therapies (CAM) a family may have tried before seeing you. This can include Chinese herbs, acupuncture, and chiropractors. An integrative approach allows families to still explore these avenues of therapy, while also accessing the various aspects of pain management outlined in this article. There is some evidence of the benefits of acupuncture, massage therapy and hypnosis in pain management.¹⁵

Family-Based and Rehabilitation Interventions

For complex situations which do not respond to the above measures in the community, sometimes a more intensive “pain rehabilitation” or family therapy approach is required

to manage pain.¹⁶ Psychiatric services and pain services often work very closely (with paediatricians) in such treatment programs. The programs can be delivered as either inpatient or outpatient and there are pros and cons to both. The current trend is to try to manage patients as outpatients with intense support if this is possible. This does require adequate resourcing of staffing to provide a seamless service to patients and their families.

My own understanding of why family therapy can be important in managing very complex forms of pain in children is as follows:

- Different parents will have different styles of discipline in the care of their children (which will involve reward for appropriate behaviour and discourage inappropriate behaviour). How parents balance encouragement and discouragement can vary. The consequence of such parenting as the child grows is that they can manage their feelings in addition to their behaviour (self-monitoring).¹⁷ One strength for children is that their developmental capacity is evolving, and it is possible to work with that as the child grows in the management of their pain.
- Persistent pain will require a combination of compassion

(acknowledging the suffering the child is going through) but also gentle boundary-setting (eg. routines). This requires a careful balance.

- The presence of pain as a symptom in a child will place pressure on the different parenting styles that already exist within a family (or extreme pressure on a single parent family).
- There will be extension of stress to all members of the family, including siblings and grandparents. Unique stresses will be present for an only child.

Some specific examples which would require a broader family intervention include:

- A 10 year old boy, Tom, with pain in his right eye where no obvious cause for the pain has been found (after neurology and ophthalmology review and MRI imaging). The parent’s relationship was already under strain before the child developed this pain. The child’s pain brings his parents together as they work on managing the pain (attending various appointments and trialling various treatments). This has included two emergency department presentations on the weekend over the past month. The child’s ongoing pain brings his parents together, and provides a distraction from the true underlying problem within the family of their relationship difficulties which also need addressing.
- A 12 year old girl, Sarah, with low back pain. She has been seen at the spinal clinic at the hospital and an MRI of her spine showed mild spondylolisthesis. Her spinal surgeon feels she does not require any surgical intervention. Previously, both of her parents had worked full-time, and the girl had received much of her care from her grandmother during work hours and after-school care programs on

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weekends and holidays. When she developed the back pain, she found her mother took time off work (and ultimately stopped working) to provide care for her. Her father remained heavily involved in his work, and much of the burden of the care for Sarah's pain remained with his wife. Sarah's mother is now considering home-schooling as her daughter feels she is unable to attend school due to her pain. Sarah has only attended school on two days in the past month. On both days when she did attend, Sarah's mother was called by the school to come and pick her up because of her severe pain within a couple of hours of arriving at the school.

Summary

Pain is a common and important symptom to manage in children. It requires a holistic and multi-disciplinary approach in both its assessment and management. There are a variety of causes of pain in children ranging from cancer to cerebral palsy. Children can experience headache, abdominal pain, and musculoskeletal pain. A thorough assessment is required, including trying to find a cause of the pain and assessing the impact on the child's quality of life and family. The management should consist of

consideration of medications, physical therapies and mind-body strategies. Self-management (motivation) is particularly important for adolescents. Pain impacts both the physical and psychological. It can be helpful not to separate the psychological from the physical (mind-body problem) but rather to integrate them (mind-body connection). Pain can have a profound effect on the child, their quality of life (school, sleep, social connections and sports/ hobbies) as well as the entire family. For this reason, sometimes quite intensive and carefully planned family-based interventions are required to best manage pain. ●

by Dr Anthony Herbert

Anthony has been director of Paediatric Palliative Care at the Lady Cilento Children's Hospital, Brisbane, since 2015. He also works within the Interdisciplinary Persistent Pain Service at his hospital. He undertook a Fellowship in Paediatric Palliative Care within the Department of Pain Medicine and Palliative Care at The Children's Hospital at Westmead, Sydney, between 2006 - 2008. He was national secretary of CMDFA from 2016 - 2011 and is the current Chair of the CMDFA Queensland branch.



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Chapter five is about medical malpractice and indemnity issues in Australia. It outlines many changes and why they came about. Such changes included issues like informed consent and the increase of litigation occurring for adverse obstetric outcomes, as well as changes in indemnity requirements and funding. Key legal cases and their sequelae are discussed.

Dr Hewson spent most of his obstetric career working in the Hunter Valley in NSW, so it is not surprising to find a chapter on obstetrics and gynaecology in the Hunter Valley. In fact even his residency years were spent at the

Royal Newcastle Hospital before leaving for England to train at Oxford.

The penultimate chapter deals with advances in Australia over the last one hundred years. Despite being information dense, the narrative style makes it very readable. Most advances are discussed in the context of who developed them and often how they came to be introduced into regular obstetric and gynaecological practice.

The final chapter, with the intriguing title 'The angels rejoice?', is an overview with an outlook to the future.

Tragedy, Trials and Triumphs will be essential reading for any person interested in the history of obstetrics and gynaecology in Australia for many decades to come.

Copies of this book can be ordered through the publisher, email sales@rosenbergpub.com.au

by Dr John Goswell

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BOOK REVIEW

Tragedy, Trials and Triumphs, Obstetrics and Gynaecology in Australia in the Twentieth Century

Rosenberg Publishing Pty Ltd, 2017

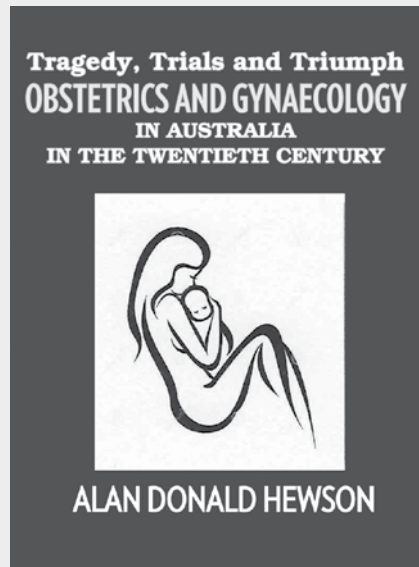
Author: Dr Alan D Hewson (1927 – 2017) AM, PhD, Hon MD (Ncle), MB BS, Syd (Hons), FRANZCOG, FRACS, FRCOG, FRCSE

This book is a “must read” for anyone interested in the history of obstetrics and gynaecology in Australia and, indeed, for anyone interested in the history of medicine in Australia.

It is well-written, easy to read and well-illustrated. Dr Hewson's narrative style is a synthesis of his extensive research on the topic and his personal experiences of sixty years working in, and teaching, obstetrics and gynaecology. To say that he has been uniquely placed to write this book is an understatement: Dr Hewson worked in obstetrics and gynaecology for sixty years, was involved in the formation of the Australian College of Obstetricians and Gynaecologists, was the last Chief Examiner in Midwifery, was an examiner for the diploma course and was admitted to the Order of Australia (AM) “for service to medicine and medical education in the field of obstetrics and gynaecology, particularly throughout the Hunter region.” Dr Hewson was also significantly involved in teaching registrars and in medical education through the University of Newcastle, from which he received an Honorary Doctorate and the position of Conjoint Professor in Obstetrics.

The book is extensively researched as a result of Dr Hewson's study for his PhD on the subject. The student of medical history will find this book a treasure trove as it is extensively annotated (33 pages of this 304 page book are endnotes, 21 pages are bibliography and 31 pages are appendices).

The twentieth century has seen more change in obstetrics and gynaecology than any other period in history. However, this book is not primarily a textbook on the evolution of obstetric procedures. It is more a book about the people who brought about these changes. It is a book that gives a feel for what it was like to be a doctor practising



obstetrics through this period of time, including the joys and sorrows of the work, the camaraderie with colleagues and midwives, and the pressures from society and institutions.

Tragedy, Trials and Triumphs is organised into eight chapters. The first is on the education of doctors in Australia from colonial days to the present. Alan places this in historical and world contexts. He traces the origins of the initial two Australian medical schools and, interestingly, the effect that differing Christian denominations had on the development of medical education in Britain and Australia. Before the 1880s, entrants into Oxford or Cambridge Universities were required to be single, male and professing Anglicans, as opposed to Edinburgh University which had Calvinistic roots and a broader intake. The differences in faith led to differences in education styles of the first two Australian medical schools. The evolution of obstetrics as a separate speciality is detailed, leading to the formation of the RANZCOG. Surprisingly the formation of the Australian College of Obstetricians and Gynaecologists did not occur until 1979. An interesting fact is that this college

was the first in the western world to require continuing medical education.

The chapter on social and cultural influences is a fascinating read, reminding us not only of the major changes that have occurred in obstetrics and gynaecology (particularly in the post-war period) but also expounding many of the formative factors, including feminism, the Catholic Church, and the changing sexual mores of this period.

In early colonial Australia there were very few midwives and most were untrained. Births were more likely to be attended by doctors than midwives: a complete reversal to the situation in Britain. Chapter three looks at the changing practices relating to confinements attended by doctors vs midwives, home births vs hospital births and medically-isolated doctors vs team approaches.

Chapter four discusses the changes in the medico-political climate. These changes included attempts to nationalise medical care in Australia, funding changes, the introduction of Medicare, the requirement of referrals for differential funding and the changes to health insurances. Trade unions tried to influence doctors as well. Dr Hewson, as president of the local branch of the AMA, received threats in the early 1970s for his publication in the *Newcastle Morning Herald* of comments that criticised the Labor government's policies. These threats included the withdrawal of petrol supplies and a black ban on any work to be done by tradesmen. The later government's policies resulted in the largest confrontation between the government and doctors in Australian history, culminating in mass resignations of procedural specialists from the public hospital system.

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Partnership in Rwandan Mission

The Anglican Diocese of Kivu in Western Rwanda is seeking for a partnership in mission with Christians having medical expertise. Its Shyira Hospital, initiated by Rwanda Mission in the 1930s, has been successfully providing health services to the communities in rural areas. The partnership of the Diocese with the Government of Rwanda has enabled the hospital to improve its services.

In July 2017, the Government completed a new hospital infrastructure (see picture) which meets modern standards including departments for maternity and neonatology, paediatrics, accident and emergency, surgery, internal medicine, and outpatients. It offers x-ray imaging, dentistry, ophthalmology, physiotherapy, and a pharmacy. To support these services there is a laundry, waste disposal, water treatment plant, incinerator and mortuary. There are also medical and nursing staff, hostels, canteen, administration, maintenance departments, and ambulance services.

The capacity of the new hospital has increased from 94 beds to 150 and now serves 202,000 people, mostly from remote rural areas at the juncture of the northern, southern and western provinces of Rwanda. The hospital uses technologies such as a centralised medical oxygen system and

telemedicine connected to Global Offsite Care in California. Good interconnection between services integrates all parts of a person's treatment. The maternity department of the previous hospital achieved a dramatic reduction in maternal and child mortality and morbidity, and it is intended to maintain this high quality service in the new hospital.

However, all departments lack qualified and experienced staff to cover all the new services. The Ministry of Health has tried to appoint some junior doctors to cover services. The most difficult cases are referred to Kigali for advanced expertise (123km away). There is a great need for specialised medical expertise in almost all departments.

The Diocese is seeking for a partnership in mission to find specialists in surgery, obstetrics and gynecology, paediatrics, internal medicine, ophthalmology, dentistry, physiotherapy or emergency. A surgeon with a range of expertise and a gynecologist are urgently needed. These medics must be able to build staff capacity and capability while providing quality services to our needy or under-served people in order to reduce transfers to referral hospitals. They might come to assist for a minimum period of twelve (12) months to work and train staff.

The Diocese is able to offer accommodation for medical experts on Shyira Hill and the hospital will provide daily local transport to and from home. The Ministry of Health will welcome any appropriate experts identified by the Diocese through this partnership. Visas and work permits will be arranged as per related regulations. The remuneration must be self-funded or mission funded.

The Anglican identity of the Diocese of Kivu is the one underpinned by the tenets of the Jerusalem Declaration of GAFCON 2008 (<https://www.gafcon.org/news/gafcon-final-statement>). The Diocese therefore invites medical experts with Christian commitment that is in line with the spirit of this declaration.

Expressions of interest: can be directed to: <http://ktpress.rw/2017/07/kagame-unveils-new-shyira-hospital/>

Further information is available:

The Rt Rev Augustin Ahimana, Chairperson of the Hospital Board of Directors and Bishop of Kivu Diocese (aamurekezi@gmail.com, +250 788 305 119) or John Steward (2live4give@gmail.com)



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My year studying at SMBC was certainly the most significant year of my life. On reflection it equipped me greatly for every endeavour I have undertaken since as I have sought to live as a child of God in his world in all I do. Spending a year completely focussed on God, his goodness and sovereignty, and dwelling day after day on his word – what he has said and done throughout history – was the best decision I have made!

Study was rigorous and of a very high standard, and I still say this having completed a PhD and being half way through specialist clinical training. But it wasn't just a thing of the head – my heart and will were continually challenged – both in the classroom and by living in the college community.