



Dealing with Disability

Disability is not something we generally think about, but when we do we imagine tragedy. We hear of a person rendered a quadriplegic and think to ourselves, "They'd be better off dead." So we say to our loved ones if that ever happens to me, turn off the machine. I distinctly remember one of our students breaking his neck, visiting him in hospital, and being unable to fathom what his life would be like. And then, in October 2010, the same thing happened to me.

Disability is not a minority topic but central to human life: The danger of speaking about disability is that the label itself suggests it's a minority topic, and so, like people with disabilities, it is marginalised as being irrelevant to everyday life. Yet, disability shouldn't be a fringe topic. On the contrary, to reflect on disability is to explore the fragility and potency, dependence and independence, constraints and possibilities, and hardships and joys that are a part of every human life.

But even at the height of our independence when we seem to have made something of ourselves, in reality we are always dependent on our families, communities, nations, and in a globalised society, the entire world. That's to say nothing of our dependence upon the natural environment. And even though we rarely admit it, our bodies are inherently fragile, always at risk of injury, illness, and permanent disability.

And as we age we inevitably deteriorate in body and mind. Old age generally involves disablement of one type or another. Far from being a minority topic, disability gets to the heart of what it is to be human. If you are not disabled yet, or you don't know someone close to you who is, then give yourself time because disability is coming for you!

Disability is not a medical condition but a social one. We tend to think of disability in terms of bodily defect. Spinal cord injury is paralysis and distorted sensation; Down syndrome is a genetic abnormality; and deafness is the inability to hear. It's a problem to do with individuals and their broken bodies and brains. As a result, when we think about disabled people (if we do), it's usually in terms of cure. We pray for a person's healing and we donate to scientists looking for a cure.

Don't get me wrong. I've appreciated the countless prayers I've received, most of which have been an expression of compassion and love. But I have to be honest and say I stopped praying for healing a long time ago. To make the most of my days, I can't live waiting for a healing that, this side of heaven, is extremely unlikely. Instead, I need to trust God as I am and make the most of my days as a disabled man. I'm Pentecostal, and it's pretty hard to be disabled in a church that links faith to healing.

I'm often asked whether my disability has caused me to question my faith. Every one of us, if we are honest, will experience times when we wonder where God has gone (and) whether he exists at all. I've come to the conclusion, though, that faith and doubt aren't enemies but go hand-in-hand. And I've also learned that the object of faith can't be healing. The object of faith is God. Faith is learning to trust in God whether or not one is healed. It's to rely on the grace of God in and through the ups and downs of life. My point is that disability is not about bodily defect and disabled people don't need a cure or your prayers.

Disability is (also) drastically underrepresented in the mediums of popular culture. This is hardly surprising because television and magazines inevitably feature perfect bodies; radio prefers

resonant voices, and the published news is focused on the powerful, the wealthy, and the famous: words rarely associated with disability.

Even on those few occasions when disability does take centre stage, it is rarely handled well. For the most part, people with disabilities are spoken about and for, rarely representing themselves. Film and television are the worst offenders, almost always employing nondisabled actors to play disabled roles. But it's acting, you might say. Yes, and so is blackface, and there's outrage when white people dare to act as black. Ironically, disabled people are either portrayed as pitiable or inspirational and heroic and almost never as simply human.

There is also a tendency to focus on those who overcome their disability. I call this the positivity myth. I can't tell you how many times I've been sent links to programs and articles about people with a spinal cord injury who, through determined effort, positive thinking, and optimism, overcome their injury and learn to stand and walk. I also get sent every new media report on the latest scientific advance that promises me freedom from the chair, whether by stem cell research or by robotics. It's the secular equivalent of Christian faith healing that celebrates the person who is healed while trying not to notice those still in their wheelchair at the back of the church.

But in praising only individuals who 'succeed' and overcome, we damn those who don't, and conveniently forget that disability is a social problem that requires a political response and social transformation; and that responsibility for such transformation rests not on the individual who must rise above his or her challenges but on our shared political will.

If disability is a social problem that has resulted in the alienation and exclusion of people with non-normal bodies and brains, then we have a

responsibility to do something about it. It is a responsibility that falls heavily on you in the published media, because you really are agents of social change. But rather than see that responsibility as a burden, I hope you might see it as opportunity and a blessing. What I discovered when I met disabled people – far too late in life – was that I benefited as much or more from their friendship as they did from mine. Human life is at its richest, not when things are easy, but when we are face to face with its challenges.

In my own case, disability has taught me new virtues. Prior to my injury, I was an almost 40-year-old successful independent man; and then I suddenly found myself utterly dependent on others for the simplest things in life; getting dressed, going to the toilet, eating etc. To make a go of this new life I had to learn a new set of virtues; e.g. patience, humility and gratefulness.

I've also had to think deeply about the purpose and meaning of my life, and I've been taught the importance of deep and generous friendship. None of this makes me any more or less inspirational than anyone else. If my story has value, it's because it reveals my capacity and incapacity, strengths and weaknesses, virtues and vices, joys and crises. It's a reflection upon what it is to try to live the good life as vulnerable and fragile creatures. I hope it's also testimony to our need for the grace of God (and) for the presence of God in and through life's challenges.

Professor Clifton, Dean of Theology at Alphacrucis College, Sydney addressed the Australasian Religious Press Association conference in Sydney. The title of his presentation was 'Church, Justice, and Disability'. He writes about his disability experiences on his blog, shaneclifton.com. He is also working on a new book 'Disability, Flourishing, and Faith' due for publication in 2017.

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