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Disability and the Dark Side of the Positivity Myth

Shane Clifton ABC Religion and Ethics 18 Sep 2014

We live in a time of global turmoil, where both traditional news and social media are dominated by the spread of terrorism, border disputes and threats of war, warnings of climate catastrophe and environmental destruction, the potential breakout of viral diseases, and never-ending accounts of poverty, famine and injustice. In this climate of fear, we are desperate for good news, and so comes as no surprise when the media choose to tell inspirational stories about people that have overcome the odds and accomplished some great success.

One of the primary sources of these good news stories is people with disabilities.

Four years ago I had a serious accident that left me a quadriplegic. Since that time I've seen (too) many inspirational stories of people with spinal cord injury (SCI), usually sent to me by well-meaning friends looking to provide encouragement. While I generally reply with a note of thanks, what I'm rarely game to say is that I hate watching these reports - that, for me, they are not good news.

The problem is that they almost always follow a predictable two-part narrative. Part one provides pictures of neck braces, helicopters, ventilation machines and shocked families, all of which is a visceral reminder of the horror of my own injury, bringing back memories I'd sooner forget. Part two describes a person's inspirational recovery, in which she or he refuses to give in to disability, and so reaps the rewards of determination - eventually stepping out of his or her wheelchair.

Don't get me wrong. I love to see people who incur a spinal cord injury recover. I don't feel bitter or jealous and I am genuinely happy for any and all recovery. My best friend in hospital, Sid, began as a quadriplegic and now walks. I recently had the joy of hearing him tell of his return to skiing on the snowfields where he had his accident. Recovery from SCI is something to be celebrated.

But - and this is my point - many people *don't* recover. And they aren't any less determined, any less (or more) inspirational, any less hard-working, any less newsworthy. Yet time and again media reporting celebrates those who recover and ignores those who don't - or worse, implicitly demeans them - as though their permanent struggles and achievements with disability are too embarrassing to talk about.

Take, for example, Peter Overton's recent [60 Minutes](#) report on Curtis Landers. Curtis is a 15-year-old boy who injured his third and fourth cervical vertebrae while playing rugby league; an injury that would ordinarily render him a permanent quadriplegic. At the time the story was aired, it was still too early to know the full extent of his recovery. But what the program was able to show was his remarkable improvement. Curtis has been able to regain function in his arms, fingers and legs, and when discharged from the hospital, triumphantly left his wheelchair behind. The program rightly celebrated the rapidity and extent of

Curtis's recovery. It also applauded the achievements of his first aid worker, whose ministrations on the football field immediately following the injury minimised the damage to the spinal cord.

This good reporting notwithstanding, *60 Minutes* couldn't help but perpetuate what I have come to label "the positivity myth." Speaking about Curtis's recovery, Overton noted that "in his mind, it was never a matter of if, but when," and followed up with the standard question: "was there ever a moment, in all honesty, when you thought 'I will never walk again?'" Curtis gave the expected response, although with some reluctance: "not really, I was planning to play [football] this season again, so walking wasn't a worry." This exchange was followed with video of Curtis at work in the gym, taking tentative steps, while John Newman and Alex Clare's inspirational song "Not Giving In" played in the background. And unsurprisingly, the report ended with Curtis stepping out of his wheelchair as he left the hospital.

Again, let me be perfectly clear. I have no issue with Curtis; he answered the question honestly, and his positive attitude toward his circumstances is commendable. His recovery is wonderful news, and it should make headlines. What I take issue with is the question Overton asks, which is deliberately framed to imply that believing in something with sufficient faith, and never giving in, will bring it about. The reality, though, is that in the early stages of rehabilitation, many people with some SCI hold on to the belief that they will recover, but ultimately have to come to terms with permanent disability.

The fact is that belief has very little to do with recovery from an SCI. When a person incurs a spinal cord injury, the long-term damage to the neurological system is indeterminate, and it takes months and years to find out the extent of the damage caused by the initial trauma. In Curtis's case, he regained movement in his arms and legs within a week of his accident, and was walking within months. This means that his spinal cord had incurred less damage than his doctor initially thought when they suggested that he would never walk again.

To do Overton justice, his *60 Minutes* report made this clear, before undoing its good work by defaulting to the positive thinking myth. Curtis's wonderful recovery had nothing to do with his expectation, faith, or positivity, and nor is it a product of his "defying his doctors." These attitudes might well have helped him deal with the emotional trauma of the injury. But mostly, he was lucky - or blessed, if you prefer. If the damage to his neurological system had been more severe, no amount of positive thinking would have kept him out of a wheelchair.

My frustration with yet another repetition of the positivity myth was echoed by others with a spinal cord injury. In response to the *60 Minutes* story, [Paul Mariager](#) observed:

"It makes out that walking is a panacea for happiness. It's everything. It's treated like an option, as though if you don't recover you don't have will power. It's unfair, it's untrue and it's dangerous. These kind of hero worship stories make out that you're either a god, or you're a quad."

In fact, people who don't recover from a spinal cord injury are capable of living the good life, even while struggling with the ups and downs of disability. My first realisation of this possibility came while I was in hospital a few months after my accident. There I met John Trefry. John had become a quadriplegic aged 19, at a time when injuries of his type were considered a death sentence. In hospital he met and then married his nurse (Pam), and together they established a home and raised two children. In 2013 he passed away after 50 years of marriage. His hadn't been an easy life, free of hardship and suffering, but it had been rich one. His was not the type of story and we hear about on *60 Minutes* (there were no reporters at his funeral), because he lived with rather than overcame his disability.

John was on my mind as I watched Overton's report, and so I wrote a response and posted on [my personal blog](#). My readership being what it is - namely, small - I didn't expect much response, although it did receive comment from my friend, Jay, who together with his wife Helena, is a parent of nine-year-old twin girls,

Jasmine and Sunshine. Sunshine has severe cerebral palsy, and so cannot walk, struggles to communicate and deals with numerous other complications arising from her disability. Parenting a child with a disability of this type has been hard work, and Jay and Helena have experienced the constancy of disability, the ups and downs, the tiredness, tears and anxiety. They also have discovered that living with disability provides moments of unfathomable love and immeasurable delight, especially when they see Sunshine smile and laugh, and as they watch the impact their daughter has upon others. They tell me that it's hard to describe the joy of taking their daughter to school, where a gaggle of her friends rush to the car to steal Sunny away and take her into the classroom. Responding to my blog, Jay observed:

"I too roll my eyes when 60mins or other shows inevitably do the feel good story about a child with CP [cerebral palsy] that walks because of the determination of the parents. Helena and I sit there and watch wishing the problem could be solved with determination - how easy would these real problems be if it was simply determination that was required to solve health issues?"

Given my focus on spinal cord injury, I'd never really thought about the issue from the perspective of cerebral palsy. Two days later, I was watching Channel Ten's [The Project](#) when they aired the story of Lia Sintras. Rove McManus introduced the account: "Now for a courageous teenager overcoming huge physical disabilities to inspire others to make every step count." What followed was a remarkable story. Lia Sintras was born with cerebral palsy, and has lived with a wheelchair all of her life. Her mother noted that at birth Lia's diagnosis was grim, with the family being told that she would never walk, nor would she be able to communicate with other children. With good reason she proudly stated that "she proved them wrong."

The story went on to describe Lia's fierce determination to succeed, evidenced when she accomplished the seemingly impossible goal of walking into her end of school formal. It was no small victory, achieved after 574 hours of training. To top it off, Lia shared her story as part of [September](#), a charity that raises funds to support people living with cerebral palsy. *The Project's* guest panellist, Todd Sampson, finished the report by summarising the lesson we are meant to learn from Lia's story: "It's mind over matter. We are often really self-limiting, and she just pushed through it."

Again, I don't want to be misunderstood. I have nothing but admiration for Lia and her family. Hers is a story that should be reported in current affairs programs and given viral fame on Twitter and Facebook. But it's also about time we faced up to the dark side of the positivity myth. The way that the contemporary media reports stories of triumphing over disability impacts upon those who don't manage to walk again. The issue is not only the nonsensical fear of wheelchairs and the general public's obsession with walking (for many with disabilities, the wheelchair provides freedom). It's that disability can't be thought away; mind doesn't trump matter, but is itself an embodied reality.

The positive thinking myth has attained the status of being the central tenet of Australia's civil faith. It is believed and propagated with religious conviction, and as such is unquestioned and unquestionable. It has its parallel in the Christian prosperity and faith healing movement. Both place too much emphasis on individual faith. Both focus on those who experience healing, ignoring and implicitly denigrating those who don't. And both fail to recognise that suffering and disability are an inevitable fact of human life, not something that can be believed away.

The positivity myth has found its way into every sector of Australian (and global) society. It is the standard fodder of the self-help industry, shapes political ideologies and informs our cultural values, and as such, it is celebrated in every medium of popular culture (television, film, music and the like). When the winner of *The Voice* looks back on her success and opines that "if you believe in yourself, your dream will come true," it's conveniently forgotten that this did not prove true for the other contestants.

The problem isn't positivity *per se*, but its object. It's one thing to make the effort to develop positive character traits and virtues (hopefulness, self-control, courage, patience, generosity), but another thing altogether to continue to propagate the lie that believing an impossible goal will necessarily bring it about -

with its corollary implication: if you don't succeed, you mustn't have exercised sufficient faith and determination. Virtue, rather than positivity, should be our goal.

In its application to disability, the positivity myth is an attempt to tame and control the bodies and minds of people whose lives we don't understand, and so fear. We celebrate only those who are able to transform themselves into our image - our normality - free from their disability. We want to believe that unyielding faith will cure cancer, determined effort will overcome the limits of cerebral palsy, strength of will can enable the quadriplegic to walk again, because we can't imagine that it's possible to live well in the midst of suffering, sickness and disability.

The irony of the popular media reporting of disability and sickness is that it's not really about disability or sickness. In fact, it's directed toward the healthy and able-bodied, intending to teach the "truths" of the positive doctrine of our civil religion. It wouldn't really matter if this was a little more than a harmless lie. But its unintended consequence is that it alienates those who are permanently disabled and incurably sick, along with their self-sacrificing and loving families.

I hope that *60 Minutes*, *The Project* and any number of other popular media platforms continue to tell the stories of people with spinal cord injury, cerebral palsy, cancer and the like. There is too much horror in the media, and we do need the encouragement of stories such as those of Curtis Landers and Lia Sintras. But is it too much to ask that we get beyond our obsession with walking, with trying to normalise people with disabilities? It's about time we heard the stories of people with a spinal cord injury who have never regained neurological function or risen from their wheelchair, but have nevertheless made a go of life with a permanent disability.

If any producer or journalist reading this piece is looking for a place to start, why not track down my friend Jay and meet his two beautiful daughters? There is one of countless other meaningful stories of people living with disability. I know of a ventilated quadriplegic that is soon to get married. I've met a man with cerebral palsy whose speech I struggle to understand, but who writes philosophy. What might emerge from such stories is more substantial than the positivity myth. Indeed, we might learn the truly profound truth that in the context of virtuous communities it is possible to flourish notwithstanding the fragility that is central to every human life.

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