

MY JOURNEY TO BECOMING FULLY HUMAN

My journey to becoming fully human really started nearly 23 years ago. I acquired my disability, a severe Head Injury, in March 1995 from a fall from a horse. I spent 4 months in a coma, a year in hospital and many years in formal rehabilitation. I now lead a very full life as a person with quadriplegia, vision impairment and full use of only one hand but I have an enormous will to live.

Disability has some undignified moments but those moments are short-lived. People with Disability were only given Human Status in Australia in 2007, the UN Convention of Rights for Person with Disability (CRPD) so this article is for all – disabled or not.

With all this talk of Euthanasia and Advanced Health Directives currently in the media, I felt compelled to put forth my own experience.

Advance Health Directive, or the ‘Living Will’ as it is popularly known, is legally binding. ‘Living Will’ is such a misnomer – it should be renamed a ‘Dying Will’. I know I can’t prevent such an option but I would like it to be clear and understood that a decision made when one is 25 years old is quite different to the one you would make when you’re 65 years old or older. I feel that as a 25 year old you lack the maturity and appreciation of life. Car insurance companies are of the same opinion.

Before my accident, I would have signed an Advanced Health Directive saying that if I had a severe accident with a prognosis of spending the rest of my life in a wheelchair – DO NOT RESUSITATE. I would have had my organs harvested and I would be dead! I would have been kept alive long enough to keep my organs viable.

All life is precious. It is against the law to commit suicide or murder. Speaking on behalf of all the people with disability, given a choice, we don't want to be devalued and have an 'upright' decide our quality of life. I know of one particular person who has quite severe physical disabilities and is unable to communicate in the traditional sense (non-verbal). His biggest fear is to be placed into hospital, not be understood and have someone decide that his life is futile.

What criterion is to be used when a life is considered futile?

And by whom? I know from reading my hospital records I was not given a lot of hope to survive. I was artificially ventilated and artificially fed through a nasal gastric tube and thankfully given every opportunity to survive against all odds. Where has the Hippocratic Oath gone? I have grave concern for future accidents and births if future legislation does not continue to safeguard the rights of people with disability to live.

The one time I found an Advanced Health Directive useful was in January 2015 when my 90-year old Mother (she was on oxygen 24/7) requested that she could die in my home. She spent her last 5 weeks living with her grand-daughter and me. She refused to die in a hospital. As I was a recipient of her Will, I had doctors come to my home every three days to prove that I wasn't attempting to kill her. When the doctors said that she should be in a hospital – I was able to produce her Advanced Health Directive. The doctors would read her Advanced Health Directive, hand it back to me and tell me to make her comfortable. I was extremely glad that Mum had gone to so much effort so I could make her final wishes adhered to.

Mum and I had spoken of this situation regularly and she was of sound mind when she was writing her final wishes. I made a promise to her see that her wishes were fulfilled. I know that

people find it hard to talk of death – there are certain members of my family and friends who don't want to know about it but please try to discuss it.

Has this experience made me want to get an Advance Health Directive for myself? No – at this stage in my life I want to be kept alive. I'm not frightened of disability. Perhaps, when I'm older and achieved more from my life – I will look into it.

Is it practical to write a new Advanced Health Directive each year? How did families and friends manage in the past? Everything has become so litigious in the 21st Century.

I do have an 'In the Event of My Death' file with my Will, paid funeral details, order of service for my funeral and my Life Insurance papers. I have spoken with both my girls of my wishes. It is vital that you speak to your family/friends and verbalise your desires so when the time comes it is one less thing to process. I'm considering a 'mock funeral'...

My life really started to turn around in the year 2000 – the beginning of the 21st Century. Bush-mechanics with disabilities – mmm... what do I mean? Practical advice and insight combined. The best way I can explain this is to say that things are no longer perfect or the same as they once were – you make do and do better with what you've got. I acknowledged that I am a Bush Mechanic with Disabilities – I am able to re-craft my life for the better. Bush Mechanic is a very unfamiliar metaphor but it can be described by using the following words; resourceful, ingenious, inventive, enterprising, pragmatic, a problem-solver, handyman, handywoman!... to name a few.

When I refer to '*bush mechanic*' I definitely don't mean '*backyard mechanic*'. I'm speaking here of people who are innovative and

choose to think and act for themselves. A dying breed - I hope not?!

I was raised in a farming family of bush mechanics and thought nothing of their ability until now, when I get so exasperated with the lack of common-sense out there. I worry about the youth of today who feel they must specialise in order to gain employment and feel worthwhile as an individual – yet, have zero common-sense. I know that the way we use our time has changed. We are often just too busy trying to survive.

There is a 4th Century Greek word '*phronesis*' which means 'wise action, practical wisdom'. It is related to another 4th Century Greek word, '*prohairesis*'. It means 'choosing ahead wisely'. In many ways we have neglected both these attributes and chosen conformity as a safe bet instead. I fear for our children's, children's future. We, as adults, the custodians of the future, are not choosing ahead wisely.

Too often in this day and age a great deal of emphasis is put on consumption without any idea of production. For an example: gone is the backyard garden which provided organic fruit and vegetables for a family. The focus is on leisure, intellectual matters and academic pursuit – gone are the people who are '*hands on*'. Do they seem irrelevant or they are just not encouraged enough?

To get my health back on track - I became free of prescription and over the counter drugs in the year 2000, choosing a more holistic path. I have now been drug-free for nearly 18 years. I had been prescribed drugs which I was told that I would be taking for the rest of my life! Big Pharma and doctors are two things I avoid. I became vegetarian in 2008 then a vegan in 2012 – first

of all, my health improved and then I found it was an excellent way to save money. With my renovations I started a vegetable and fruit garden in 2015 - now it supplies our household of about 60% of our food.

Getting innovative - in recent times, I have had to see to develop this capability. I use things that may not always be for their correct use; for example, I use a reinforced towel rail in the bathroom for support when I'm transferring into the shower chair from my wheelchair, which also doubles as somewhere to hang a towel. I use the iron bed ends for support when I get dressed or I use long food tongs to reach things that I can't reach from my wheelchair. There are many things around my home which are not used for what they were made for.

Another example, is I use the protection board on the flyscreen door to close the front screen door when I come in from getting the mail as I can't reach the door handle. If I'm on my own, I enter my home by coming in backwards as my front door is too narrow for me to push the wheelchair with my hands. Same as my bathroom door is too narrow and my bathroom is too small for me to turn around so I can exit the room forward. These things will be rectified with the introduction of the National Disability Insurance Scheme (NDIS) starting July 2018.

I started to renovate my home in 2014 to suit my needs using Universal Design principles. I am about 75% size-wise (area) complete – about 60% financially done. I expect to be fully completed in 2020. I have become incredibly patient – had I rushed these renovations, I would have made many mistakes. As I chose to live in my home as the renovations were being done, there are no mistakes. Fixing mistakes can be a time consuming and a costly exercise. The final section to be done

will allow me to enter any space in my home, allow me to freely and safely exit and enter my home, to be able to close the bathroom and toilet doors after nearly 23 years of being exposed to all and sundry! When I was an *'able bodied upright'*, I took so much for granted. Now when I'm challenged by the simplest of tasks, I readily become a bit of a 'bush-mechanic'.

Also I have started a small business, Aesthetic Home Access in which I can use my experience of renovating my own home to help others create a liveable environment and now with the introduction of the NDIS, people with disability no longer have to live in sub-standard accommodation. I wish to use my home as a display home to show what can be achieved by retro fitting an existing home. The house needs good 'bones' to be suitable. Building a new home from scratch is the more economical way to go but the infrastructure of the environs is quite often non-existent therefore retro-fitting an existing property.

Furthermore all this adds to a *'re-design'* of my lifestyle and work-style from the ground up. In doing so, I have had to take responsibility for this process and to change things when they don't work. This design work includes re-thinking my lifestyle and work-style, re-designing my living and working arrangements to fit and then implementing this design by re-working my living area with computer access, grab rails, home access design, wheelchair access, design and so forth – all the while looking aesthetically pleasing.

In short, I have had to be directly involved in the idea, the design and the implementation of my life and work styles. This upheaval has taken some 23 years to solidify into a *'workable'* and *'liveable'* interdependence.

I have learnt to source out facilities where I am respected as a citizen with disabilities. I have also learnt to make a stance on the behalf of other disadvantaged citizens and this has at times meant challenging the 'status quo' in private enterprise. Having been a small business owner myself, I am aware of the apparent conflict between profit motives and exercising a civic responsibility. People with disabilities contribute a small percentage of dollar turnover - we are however a small, yet I maintain an important, minority to business.

A private enterprise which makes appropriate effort for the special needs of those of us who are disabled, makes a community statement, it sets itself apart from the average competitor and is generally assured of a loyal and returning customer base. People with Disability are often, out of necessity, opportunistic (and sometimes impulsive) consumers which translates to a higher than average dollar spend. I call myself an 'opportunistic optimist'. Additionally, with all the advances in medicine and mechanics, we are fast becoming a mobile movement in our own right.

Also in September/October 2009 I added another adventure to my life – **I travelled around the world.** There were many occasions where my '*bush mechanic*' skills came to the fore when I was having to make do with what facilities were around in a foreign environment.

Using disabled facilities away from my own environment is always a new challenge. When you are out of your '*comfort zone*', you suddenly find all sorts of talents you did not know you had. I make a point of congratulating myself on finding a way around these challenges failure was literally, not an option. *Failure is daring not to try.*

Being a *'bush mechanic with disabilities'* works for me, it allows me to become a *'squeaky wheel'* or *'dripping tap'* and therefore it gives me time and space to work out the best way to go about achieving a successful outcome. I know my form of patience would *'frustrate the heck'* out of many people but it works for me. Before, when I was an *'upright'* I used to jump head-long into things and regret it later.

Sure, I'd look busy but casting my mind back, I would have had more successful outcomes if I had taken the time to think again about it, design and re-design a response, implement the design and see how it worked, while all the time being prepared to change it and learn - in short, to do it properly.

DIN and DIP – “Do it now and Do it properly” – by NOW I mean my sort of NOW. I'm very deliberate with my type of NOW - I *'frustrate the heck'* out of many people.

I did not always *'choose ahead wisely'*. Ah, we all have 20/20 vision looking back. Now I seek to *'choose ahead more wisely'* and to this end I started keeping a record of my lessons learnt – ultimately, they became my first book “Permission To Shine – The Gift” and have provided the foundation for my second such effort “Shining On”. To write my book I had to acknowledge my deficits, work around them and by its end, I can say that the whole thing was written with one finger! I have a third book on the go called “Still Shining”.

I would also like to quash the myth that some-one is better because they have a qualification and/or letters after their name. I would rather be on a desert island with a practical *'bush mechanic'* than a doctor with heaps of letters after his or her

name who did not know the difference between a screwdriver and a hammer. What would be ideal is if I was on a desert island with a '*bush mechanic*' doctor!!

Progressively over nearly 23 years I have slowly come to realise what it is to be fully human and, I see that being fully human means for me - *is living as best as I can with what I have got and encouraging others to do likewise and develop their potential towards being fully human.*

Being fully human is also about *a deep recognition and respect for Dignity of Disability.* Disability is a vital part of being fully human it is not a 'deviance' to be eliminated by *genetic engineering.*

To be fully human is to be altruistic, recognising the need to support and be supported with others in working towards the common good. It doesn't need to be all about money – pay it forward and you will receive in ten-fold.

I am a proud, bolshie person with disability who likes to question the 'status quo' and indeed if I didn't do this I would simply be dead. I have lived experience and know how to make my disability work for me. For so long (5 years) after acquiring my disability, I felt de-valued and far from human – I was in fear of being euthanised and people watching/allowing it to happen.

I am thankful for the medical intervention I received in the early years when I had my accident and I appreciate the technological advances in equipment and prostheses. We need however to balance intelligent technology and messy humanity. Ultimately, what proved of key importance in my survival was the latter and thus becoming fully human and being able to critique

technology and select it to assist me rather than the other way round is crucial. This is a skill I am still learning and I would like to bottle and send gratis to other disabled folks.

Now in the 21st Century I am fully human and incredibly excited about the future. In Australia the future being the National Disability Insurance Scheme (NDIS) where people with disability can live an ordinary life with reasonable and necessary supports has enormous potential to help differently abled Australians move towards being fully human.



My back deck, vegetable garden & studio.

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