

**if
these legs
could walk...**

Dean Phillip Paul Coulston

Adelaide 2014

if these legs could walk...

A journey by
Dean Phillip Paul Coulston
with a little help from his friends

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Designed, printed and bound by
Digital Print Australia
135 Gilles Street Adelaide South Australia 5000



Do not see my disability as
the problem.

Recognise that my disability is
an attribute.

Do not see my disability
as a deficit.

It is you who see me as deviant
and helpless.

Do not try to fix me because
I am not broken.

Support me. I can make my
contribution to the community
in my own way.

Do not see me as your client.
I am your fellow citizen.
See me as your neighbour.
Remember, none of us can
be self-sufficient.

Do not try to modify my
behaviour.

Be still and listen.

What you define as
inappropriate may be my
attempt to communicate with
you in the only way I can.



Extract from
A Credo of Support
written by
©Norman Kunc &
Emma Van der Klift

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Introduction

I decided to write this book to help increase awareness within society that people with disabilities are normal people.



Hopefully the reader may become aware of the many types of disabilities some people face and live with in their lives every day.

Hard times are faced and conquered by everyone in one form or another, and disability or no disability, we are all the same.

I'd like to thank everyone who has helped me along this journey, especially my parents Geoffrey and Pat, and my sisters Dallas and

Stacey for their unending help and support.

And to my 'ghost writers', Sasha Hewitt and Jenny Brown, thank you very much.

I hope you enjoy my story.

Deano
Adelaide, 2014

Who is Dean Coulston?



He is Dean Phillip Paul Coulston (who prefers to be known as 'Deano' and has it tattooed on his right hand in case you forget!).

At the time of producing this book he is 36 years of age with black hair, brown eyes, earrings in both ears and tattoos, including a Tasmanian devil on his right shoulder blade, a dragon and an eagle on his right arm and on his left arm IGK (a martial arts group).

His favourite food is chocolate mousse and his favourite drinks include Coke and iced coffee.

Football and martial arts, karate in particular, are his favourite sports. He also likes State of Origin Rugby and supports the Maroons. It should also be noted that he is a Cowboys supporter, except when they play the Northern Eagles.

Deano likes nothing more in life than being with good friends.

This is his story, which includes extracts from his early life in the eastern states and in South Australia.

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The young Deano



People need to spend a day in a wheelchair to understand what it is like for us every day



I have severe spastic quadriplegia cerebral palsy, but in a sense I have had better opportunities than some people with similar disabilities. I have not had to spend my life in an institution and my parents have been very devoted to my personal development. While I was at the Spastic Centre my parents would sit me in front of a mirror to help me learn to speak. At first it was hard getting my mouth to do things that it hadn't done before and I was four years old before I learned to talk, but the work was worth it because now I can speak and write this book. Now I want to have the opportunity to help others who have been less fortunate than myself. I am angry, confused and upset about the way society treats people with disabilities.

If people once in a while helped others in the community with disabilities, the world would be a more tolerant place. People need to spend a day in a wheelchair to understand what it is like for us every day. They need to understand that we are just like them except that we are in a wheelchair. We have different abilities and talents just like everyone else. I don't think that I have ever really been treated "normally", especially by people when they first

meet me. People who haven't had the chance to get to know me always see the wheelchair and not the person and it makes me feel upset, angry, confused and even mad. I've never gotten over it. People stare too much. I wasn't born to be a spectacle! Every time it happens I feel like asking them what they think they are looking at. I can share a joke with good friends, like my friend Donna who gives me a hard time whenever I see her, but sometimes people hurt my feelings.

I think of myself as an able bodied person. When I was about fifteen months old I started doing a commando crawl using my elbows and I can still do this when I really need to. I never learned to walk and have always used a wheelchair to get around. But I can't think of myself in a wheelchair. I like to think of myself as a person who can go out and do things, not as a person in a wheel chair. I've been in a wheelchair since day one and it's really frustrating me. It's made me angry. I don't understand how people can't look at me as a human being. A lot of times people don't give me credit for being a coherent, intelligent individual. I want to teach "normal" people not to be afraid of wheelchairs. They don't have to be afraid of us; we're just like them but in a wheelchair.



I hate the word "spastic".

I don't like being called spastic. We're not spastic, we just have problems communicating or have speech impediments. I mean, even those who can't talk don't like to be called spastic. When I was at Regency Park School in Adelaide a couple of my friends had Bliss boards, typewriters that could speak and they didn't like being called spastics. It made me angry and it made them angry.

They have a mind, which can understand what people are saying. What they don't have is a body that will let them do everything for themselves and a voice to speak with. They need more help than others. That is the only way they are different.

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My Family



I have this tattoo on my upper left arm. I have to keep explaining to Dallas that it doesn't mean Stacey is my favourite sister ... I love them both the same.

I live in Adelaide's northern suburbs with my parents, Pat and Geoffrey, although mum spends quite a bit of time in Townsville with my nan (her mum) who is getting on a bit. I have called my father Geoffrey for a long while now because he tends not to listen if call him dad. Geoffrey is a semi-retired security guard and mum is a volunteer worker in palliative care.

I have two sisters, Stacey and Dallas. Stacey is older than me and married to Dennis. They have two boys, Shaun and Hayden. They live in Adelaide. Stacey works in a nursing home and Dennis is a mechanic, but they are both actually chefs by trade.

Many years ago, Stacey and one of her friends put an advertisement in the local paper's lonely-hearts column. It started of as a bit of a laugh but Stacey ended up with more replies than she ever expected. Dennis was one of them and they have been together ever since.

When I was younger and living in far north Queensland and we would go down to Adelaide,

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Dennis would take me out to the drag races ... and makes us mousse. Yum! He actually used to race his Holden Gemini in the drags.

My other sister is studying to become a nurse. Her boyfriend, Jason, is a structural draftsman. Dallas and Jason met through bowling. Jason has always helped me when I've been stuck on things and I have begun to think of him as a brother. Jason and Dallas used to live with us, but now they have a baby, Genevieve, they've moved into their own house nearby.

I have a whippet named Cash that I was given at the Townsville Show and a white Persian cat, which I call Snowball. We also have a Chihuahua named Chewy and a black cat named Shadow.



My Medical History

I was born at three o'clock in the morning on 1 April, 1978 at Fairfield Hospital in Sydney. I was 3 months premature and weighed 2 pounds, 4 ounces. At that stage, Fairfield Hospital was full of premature babies so I was sent to the neonatal unit at Camperdown Children's Hospital. It was a worrying time for my parents as my mother, Pat, remembers well:

“

He actually died on the way to hospital; then he died three or four times in the hospital.

”

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“He actually died on the way to hospital; then he died three or four times in the hospital. Then they told us all about the problems that he had and it hit us like a brick. Dean was the second living child. We had two others die before him – miscarriages. He got meningitis and he had blocked ventricles at the back of his neck.”

At two weeks of age, the doctors discovered that my head circumference was larger than normal. After a few tests they discovered a blockage in my brain caused by a ruptured blood vessel, which in turn caused hydrocephalus, or fluid on the brain.

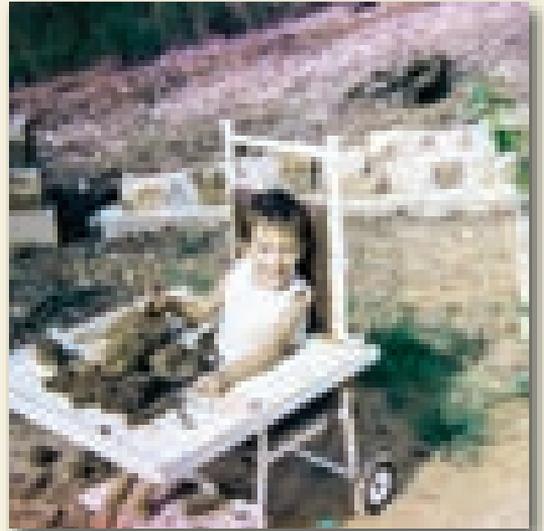
After talking to my parents, they decided to put a shunt in to drain the excess fluid. I had another three operations in the next month. Over my life to date, I have had about twenty-eight shunt reviews, which means that they have had to replace the shunt, due to a problem such as a blockage.

When I was about six weeks old, I developed meningitis. They put me in isolation and had to drain the fluid externally.

I finally went home when I was four months old when my family moved to Grafton on the New South Wales coast, north of Sydney. At six months of age I started having seizures. About four months after we moved, my shunt blocked again and I had to be flown back to Sydney for a shunt review. My mother, Pat and Geoffrey first found out that I had Cerebral Palsy by chance from a physiotherapist when they took me to Sydney on this trip and mum checked with my doctor, who said he thought she knew. She says he said didn't you realise he couldn't sit or do anything normally. She told him she had not because I was three months preemie to start with and had so many operations that she and Geoffrey just hadn't thought about it

They were referred to the spastic centre of NSW and saw the doctors there. They explained what could be done. Because we lived 500kms north of

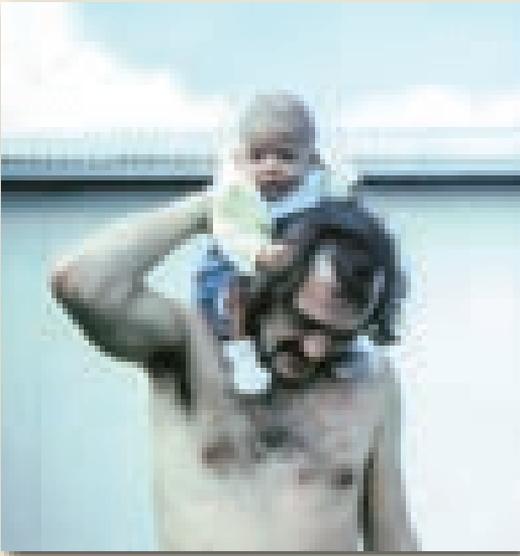
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My family ensured that I had the best possible childhood. Geoffrey modified chairs which allowed me to play with mud like any other child. In the photo at the top left, I am holding a toy motor bike which apparently I would not let go of ... night or day!



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**FROM
DEANO'S
SCRAPBOOK**

*My need for speed was encouraged
from a very early age by Geoffrey.*

*Australia II's historic America's Cup win of 1983 inspired
him to add a winged keel to one of my early wheel chairs.*



Sydney when all this was happening, they made an appointment to come back down. We'd go down and spend a week there so that I could have physiotherapy, occupational therapy and speech therapy.

When I was five I started school, I had to board at the Spastic Centre and mum would come down for a couple of weeks every term to help look after all the kids in exchange for them looking after me. There were children and adults, but they had a workshop for adults. It was a huge dormitory thing. My parents used to pick me up for the holidays.

I had ongoing operations for my shunt. The doctors told mum that the meningitis that I got when I was six weeks old caused the cerebral palsy, but she says my birth wasn't easy either. They actually had to kneel on her stomach and push me out. She has got a few theories.

I was aged seven when we moved from Urunga to Adelaide. Someone had mentioned that there were excellent facilities at the Crippled Children's Society in Adelaide. So we decided to move over to Adelaide and get a bit more treatment over there. I went to school in Adelaide until I was about sixteen. We moved up here from Adelaide when I was sixteen and because there weren't very many facilities for disabled people we had a lot of trouble getting me into a school.

When we first lived in Adelaide they used to have visiting specialists come in to the schools and here's what mum has to say about that:

"Because Dean had really severe cerebral palsy, he's classed as a spastic quadriplegic, all his legs and feet and that, the tendons were so taut that they used to have releases. I think he started With a hip release. They used to plaster his feet to try and turn them. He'd have his feet plastered to the knee. That was when he was young, only about three years old. He's had hip release, hamstring release and Achilles. He also had a



...she says my birth wasn't easy either. They actually had to kneel on her stomach and push me out...



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Grice procedure, which is where they take bone from the shin and stick it down into the ankle and put a pin in to hold that bit of bone in the feet to try and turn them. All of which never worked in the long run. So I'd never recommend following medical advice if they say: 'We might try ...'

There is no such thing as we might try: it's 'We'll experiment ...' Dean felt like a guinea pig. In the end, the orthopaedic surgeon Dean was seeing because his toes cross right over said that the only thing that you can really do with that is cut the toes right off. So that was the last time we ever saw that orthopaedic surgeon. We told him where to go. We never ever saw another orthopaedic surgeon. None of it ever worked all this time.

His first shunt was a ventricular-peritoneal, which drains into the abdominal cavity. Something went wrong there so they drained it into the right lung with a ventricular pleural shunt. Something went wrong with that one so they took it out when it blocked again and then they put it in the other side and then they put it into his heart, to drain the fluid into the heart but when they did that, I think he was three; he developed golden staph in hospital so they had to take it out of the heart and drain it from inside out. He had to have an external drain until the golden staph cleared.

When that cleared they put the shunt back into the peritoneal cavity, and he's had that ever since.

When Dean was five he had an operation to correct a lazy eye. He's had operations for all sorts of things. A couple of years ago he had an operation for ingrown hairs in the crack of his bottom. That wouldn't heal. It has healed probably in the last month and it's been two years. The stitches wouldn't hold. And then he had appendicitis last year and they couldn't find them. They were around the back. His intestines were all twisted around together."

Despite all these operations, at the moment I'm as fit as a fiddle. I have epilepsy and just before I

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have a seizure I get a headache behind my eyes. I was at the movies one time and they had flickering lights, which caused me to have a seizure, but my epilepsy is managed now with medication and seizures are rare, although I still have seizures when I'm stressed out over things.



During schooling at Regency Park

School

When I was growing up I had trouble fitting in. I found that other school kids and even teachers used to pick on me. I first started going to the Spastic Centre in Sydney when I was five years old. I had to board at the school and my parents went down for a couple of weeks every term to help look after all the kids there.

The Spastic Centre was for both children and adults but they had a workshop for adults. I slept there, I ate there, and I did everything there until my parents picked me up for the holidays.

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“

...he called out
“There goes a
retard” ...
I rammed him with
my wheelchair...

”

I believe that early integration would be beneficial for kids with disabilities. When my family and I were living in Adelaide, I was not allowed to go to a “normal” school. I attended Regency Park Special School from the age of seven but I was never really happy there because I felt like I was unable to express myself as a person.

While going to school at Regency Park I learned to swim and enjoyed taking part in the school swimming carnivals. However now the only swimming I do is in our pool at home during the summer.

We moved to Townsville when I was sixteen. My parents had a lot of trouble initially getting me into any school because there were not many facilities for people with disabilities. Eventually, the

education department suggested Aitkenvale Special School. I attended Aitkenvale for about six months and it nearly drove me insane. I was not able to communicate with any of the kids there. I tried to talk to the teachers but I was told to go and play with the kids. I felt trapped. So I stopped going to school.



Geoffrey has customised my chair in many fantastic ways which has increased my mobility considerably. I have a reversing camera as well, and my number plate is “2 TUFF”.

Finally we found the Special education unit at Kirwan State High School. I attended this mainstream school for my final two years and met Matt who became my best friend. Matt was a great help to me while I was at school. At Kirwan one of the subjects I studied was photography, learning how to take photos and develop them.

I never fitted in very well at Aitkenvale, but I found I was much better suited to Kirwan High even though some kids called me a ‘retard’ and others