

D.O.B.: [REDACTED], 1961

SENATE INQUIRY Support for Australia's Thalidomide Survivors

Impact of Thalidomide on my Parents

In the words of a current television program title - I live a '**Body Bizarre**'!!! I have missing limbs to my body and I have other body parts protruding from places, not normally expected. I am a victim to Thalidomide and this is *My* story.

My biological Mother ingested one (1), maybe two (2) tablets of the 'wonder drug', Thalidomide, in the early stages of my limb formation, while I was in utero. My mother was totally unaware that in an attempt to relieve her own medical symptoms during pregnancy - she was unwittingly becoming part of the world's greatest medical disaster! Through her actions of attending to her own medical needs she was oblivious and innocent to changing the trajectory of our lives - forever! I know she and my Father took the subsequent guilt to their graves.

My Mother saw me for two (2) hours after my birth - my Father never saw me! My life was signed over to the State (Western Australia) within 72 hours, which immediately denied me any parental bonding and nurturing from the very first hours of my life.

My Mother did not know: -

- That Thalidomide was an untested drug in Australia,
- That the drug manufacturer possessed prior knowledge of the significant effects Thalidomide had already had, on unborn fetuses, and
- That she would relinquish her baby - believing she could not attend to the demands of my significant physical disability.

Government Responsibility

The Federal Government failed my Parents (and me) when it: -

- *Allowed Thalidomide - an untested drug, into Australia - whilst knowing **Dr Francis Kelsey's** (Canadian-American pharmacologist and physician) hard-fought campaign that Thalidomide was unsafe for distribution in the United States;*
- *Shirked its responsibility of taking blame for allowing an untested drug into Australia;*
- *Did not immediately withdraw Thalidomide from the pharmaceutical market, hospitals and homes (unlike New Zealand), thus allowing further damaged babies to be born;*
- *Did not provide a coordinated Thalidomide Trust (similar to England) offering counselling support and service coordination, for parents giving birth to deformed babies;*
- *Did not provide immediate financial assistance, in the face of the large medical costs that were envisaged and,*
- *Establishing the Therapeutic Goods Administration (TGA) after-the-fact and to the exclusion of all other supports was of no comfort, consolation or consequence for my parents - the 'horse had already bolted' for them.*

Impact of Thalidomide on my Childhood

At the age of three (3) I was flown to Melbourne where I lived at the Royal Children's Hospital (RCH) for about 18 months. There, I was fitted with a range of prosthetics (both legs and arms). The aim of the prosthetics was to make me 'look normal' and increase my ability to undertake tasks. The reality was that the limbs were very heavy (arms were powered by two (2) gas cylinders worn on my back); physically painful and hot to wear; caused me injury to my unprotected face when I regularly fell over; caused me tremendous emotional distress and, most importantly - thwarted my own natural abilities! I ceased wearing them at the age of seven (7)!

D.O.B.: [REDACTED], 1961

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The cost of my prosthetics was only made possible by a single appeal held for me by the [late] *Johnny O'Keefe*, on his daily radio breakfast program in Perth, Western Australia, prior to me leaving Perth.

During my extended period at the RCH, a Melbourne-based foster family created an indefinite place for me. Our 'Mum', a single woman; a trained physiotherapist and, an experienced foster mother - had the confidence of the RCH doctors and allied health staff, as she had previously held a senior position within the RCH Physiotherapy Department.

Government Responsibility

With the needs of Thalidomide-affected children becoming more known and publicised, the Federal Government failed me in its duty to: -

- *Provide a coordinated approach to prosthetics, aids and equipment.*
- *Provide free prosthetics*
- *Provide paediatric counselling and support for me, a traumatised infant/toddler.*
 - *I have a vivid memory of 'men in white coats' wrapping me in plaster, cutting me out of semi-set plaster moulds used to create heavy and cumbersome fibreglass prosthetics. They virtually practised on my body - translating their Returned Veterans knowledge, onto a toddler.*

Impact of Thalidomide on my Childhood - cont.

At the age of three (3) I finally had a 'home' - with seven (7) other children/young adults - all with a physical disability. My previous institutionalised life gave me no concept of what a bedroom, kitchen or lounge room were and, I would panic when I could not see an adult. My pale complexion from living indoors, would burn and blister - even in the shade.

There was no tolerance for 'woe is me' in our family. I know this prevented me from asking questions about my disability. I was around 11 years old before I was told my disability was from Thalidomide. I could not even utter the word '*Thalidomide*' until I was well into my 20s, as my condition was spoken about in hushed tones around me, which had me believing Thalidomide was a 'bad word' and, one for which I felt shame.

My '*can-do*' attitude was probably my strongest asset, however - while simultaneously feeling like an additional impediment in my life. I felt crushed every time it was 'translated' into [REDACTED] *has rose-coloured glasses*'. I believe this 'protectionist approach' significantly thwarted the development of my innate physical capabilities. My foster Mum insisted I wear sleeved dresses - to cover both my hands and feet in public, so as not to '*draw unnecessary attention*'. In my childhood, I used my feet for everything - grasping a book, writing, knitting etc. - I became shameful of my feet and hands.

I believe this protectionist approach (whilst very well-meaning on my Mum's behalf - and likely to be meeting State requirements to not exploit the uniqueness of my disability) resulted in reduced expectations of me. I was told I was too hard for others to *manage* me on school and church camps; attend a school evening dance/disco; attend friends' homes; at Youth Group or, at Sunday School. If ever my working life was considered, there was an expectation that I would pursue an accountancy career - as I could work from home and ... "not need to be in the public".

D.O.B.: [REDACTED], 1961

SENATE INQUIRY Support for Australia's Thalidomide Survivors

Had I been raised as the only child with a disability in the family, I could well have thought I was being protected *because* of my disability. However, as all in the family had a disability, I felt it was the *uniqueness and severity* of my *Thalidomide deformities* that were 'singled out'. I watched my foster siblings being encouraged to go shopping; swim in our home pool; attend Youth Group and, go out with friends - as they were sufficiently able to independently get in and out of the pool or a vehicle. I suffered greatly watching them from the window - playing in the pool or seeing them being driven off on an outing. *I felt very alone.*

My Thalidomide disabilities became my enemy and, the cause of my lifetime of depression.

Impact of Thalidomide on my Adulthood

Depression

After completing my Higher School Certificate (HSC) I spiralled into a very deep [clinical] depression. I felt I had no future. I had completed my secondary school studies - but for what? I could not nominate for any university courses as I had no way of getting to and from any campus. Who would want to employ me? ... What could I do anyway?

I sought professional counselling, but it sapped me of my [limited] emotional reserves explaining my life and particularly, my Thalidomide disabilities. I could find no-one for whom *I* did not have to put *them* at ease - in order for me to begin exploring my depression.

My Mum suggested I apply to attend a sheltered workshop (supported employment). It was inconceivable to me that I would ever attend a workshop ... however, I did not want to stay at home in my depressive state. Thankfully - I was declined a workshop position, as my academic achievements were considered too high.

Further Study/Work

I learned of the advent of multipurpose taxis during my year of depression. I was accepted into Chisholm Institute, (Welfare Studies) and a number of years later attended Monash University (Bachelor of Social Work). As a result, I successfully gained locum work and later permanent employment within the Commonwealth public service.

It was essential for me to have two (2) motorised wheelchairs in order that I still had mobility whilst the batteries were being charged overnight. I *self-funded* my wheelchairs. The Australian Taxation Office (ATO) considered motorised wheelchairs (and on-costs) to be 'luxury items', thus refusing these as 'medical costs' for tax purposes.

When commencing employment, I was receiving Council Home Help. It was a totally foreign concept to them that, I had taken the initiative to gain employment but, when the Council would only provide my in-home domestic support if I was present in the home. I challenge their previous policies ... and won!

Government Responsibility

The Federal Government once again, *failed me* in its duty to: -

- Provide counselling supports/funding to attend my mental health;
- Provide ongoing financial support for aids and equipment and Council Home Help;
- Provide support in finding post-school options;

D.O.B.: [REDACTED], 1961

SENATE INQUIRY Support for Australia's Thalidomide Survivors

- *Provide mediation supports in my battle to maintain receipt of Council services whilst working and,*
- *Provide mediation supports with the ATO re 'luxury item' label given to motorised wheelchairs*

Independent Living

I chose to move away from home at the age of 23. I was very relieved and very grateful to have my Mum's support - which I recognise, for her, would have been very difficult. Given the significant modifications required (primarily kitchen and bathroom), renting has never been an option for me. Costs of home modifications are huge!

As I lack limbs, heat regulation to my body has always been difficult. My skin surface is insufficient to relieve heat/temperature from my body. In the winter I feel the cold terribly. I am unable to wear thick clothing as it restricts my limited movements too much. I therefore rely heavily on heating and cooling in my home - which is an additional cost to my disability.

Clothing is both an emotional and costly exercise for me. Emotionally, I am frustrated that I cannot just 'walk into' shop clothing. My body proportions have my hips more than four (4) sizes bigger than the rest of my body. *Every* piece of clothing I purchase, must be altered - *at least* in the hip range and *always* at my hands to avoid sleeves being floppy and [accidentally] catching on the joystick of my wheelchair control box and, for safety when I drive my vehicle. I must factor in alteration costs to *every* item of clothing I purchase.

I have a very poor body image due to my obesity and rarely look at myself in the mirror. I have had a lifetime of being on diets and have undergone a range of radical surgeries to address my obesity. I had breast reduction surgery when I was 27 years of age. In my 40s I had fat removal surgery to both legs and an apronectomy (removal of fat from stomach area). After much professional dialogue and thought, my plastic surgeon (six (6) years ago) agreed to my *plea* for a double mastectomy - purely for *functionality* purposes. The action of, and energy required, to put a bra on had become almost impossible for me. My toes, neck, back and shoulders had increased arthritis, which reduced my abilities to grip and manoeuvre my body and, my teeth were becoming too fragile to continue the act of getting into a bra. Additionally, my reach to my dinner plate was seriously impeded as, my one (1) usable hand, was not long enough to reach past my breasts to my food. I received no financial support from Medicare or my private health fund, despite written evidence provided by my general practitioner and surgeon! Mutilating my body in such a drastic way did not constitute as elective 'cosmetic surgery' for me!

Yes, I am very blessed to be able to drive a motor vehicle - but this has come at a great cost. With the amount of modifications required to ensure driving was a safe activity for me, it was unrealistic to purchase anything other than a new vehicle on the two (2) occasions I have done so. My first vehicle took four (4) years and my second, 18 months - to modify. I had no financial assistance whatsoever in meeting the modification costs of either vehicle. The *modification costs* of my second vehicle equalled the amount of the vehicle itself!

Government Responsibility

The Federal Government most certainly failed in its responsibility to assist me throughout my adulthood by not providing support for: -

- *Home modifications*

D.O.B.: [REDACTED], 1961

SENATE INQUIRY
Support for Australia's Thalidomide Survivors

- *Costs to assist in regulating my body heat;*
- *Costs to clothing alterations;*
- *Medical costs for radical Thalidomide-related surgeries and,*
- *Costs towards extensive vehicle modifications*

Impact of Thalidomide on my Future

My response to this section is short, true and frightening – I DO NOT KNOW!

What *I do know* is that: -

- I am tired of educating people!
- My body is failing me!
- My emotional resilience is running out!

No medical professional can possibly accurately determine what my future will 'look like'. No one knows - as there has been no one with *my unique set of man-made deformities* - to gauge what my future will be. What *I do know* to be *my truth* is, that I will undoubtedly require supported facility-based care within the next 10 years!

What I also know to be the truth is, that other [comparable] countries have accepted their moral obligation to provide compensation to their Thalidomide Victims. It is shameful that Australian politicians (of all persuasions) have failed to 'own their responsibility' for allowing an untested drug into our country - without consequence! For nearly 57 years I have worn the consequence of the government's inaction! Is parity with comparable countries too much to ask? I don't think so!